INFLUENCING AWARENESS OF DISABILITY;

USING INFORMATION FROM

PATIENTS WITH LEARNING DISABILITIES

A project submitted to Middlesex University in partial fulfilment of the requirements for the degree of Doctorate of Professional Studies in Health

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ABSTRACT

We know that people with learning disabilities are more prone to a number of medical conditions including epilepsy, dental problems, hypertension and respiratory problems (FPLD 2006). Conversely we also recognise that people with learning disabilities have significantly poorer health outcomes (WHO 2001).

Valuing People (DOH 2001) set out to improve the lives of people with learning disabilities by, among other things, reducing health inequalities and improving access to healthcare. The strategy introduced Health Action Plans (HAPs); documents prepared by / with a person with learning disabilities covering information about their health and health choices. It intended that HAPs would have been integrated into health service culture by now but the task of completing one with every person with learning disabilities is proving to be quite challenging.

This project involved the development and implementation of patient held hospital passports in an acute hospital. The project team included staff working in an acute hospital and community learning disability teams; extensive involvement from service users, carers and organisations supporting people with learning disabilities underpinned the project. A passport, like an HAP is completed by / with a person with disabilities; it contains information considered necessary for a hospital appointment / admission. Ultimately it is intended that the passports will form part of the patient's HAP once that has been completed (possibly as an appendix) but it is also designed as a stand alone document.

Evidence appears sparse regarding the assessment or evaluation of awareness levels of staff in acute healthcare settings regarding the needs of people with learning disabilities. This project looked at whether the use of hospital passports would support this. Staff awareness was measured using the nominal group technique to establish consensus regarding the challenges that healthcare staff face when working with patients with learning disabilities. In a six month period, twenty patients with planned (elective) admissions used passports during their stay in hospital. The implementation of the passports was supported by training sessions to

inform staff how to use them. Nominal groups were then conducted with staff who had worked with patients using passports. Consensus of opinion showed that the passports had made a difference to staff when working with patients with learning disabilities. An increase in staff awareness of learning disabilities was also identified. The patients' perspectives were also considered; evaluation forms were completed after discharge with sixteen patients who had used passports during their admission. Patients reported that they felt their passports had supported communication during their admission and improved their overall care experience.

The effectiveness and limitations of the project design are addressed and the ethical implications of working with patients with learning disabilities are discussed. Recommendations for disseminating the use of passports throughout the hospital and with other local healthcare organisations are also outlined.

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CHAPTER 1

CONTEXT, PURPOSE AND AIMS

1.1 INTRODUCTION

The 1995 Disability Discrimination Act (OPSI 2005) stipulates that it is the duty of public sector organisations to promote equality for its service users. In 2005 the Act was amended to legislate that organisations must make provisions regarding access to information and services, including of course, healthcare assessment, treatment and information. The act defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

On 31 May 2007 (after the commencement of this project) the Secretary of State for Health announced the establishment of an Independent Inquiry into Access into Healthcare for People with Learning Disabilities. The aim of the inquiry (which aims to report its findings late July 2008, after the writing of this report) is to identify the action needed to ensure adults and children with learning disabilities receive appropriate treatment in mainstream health services (IAHPLD 2007).

1.2 LEARNING DISABILITY

The term learning disability can be subject to misuse and misinterpretation due to the lack of awareness that surrounds it. Valuing People (DOH 2001, page 14) states that a learning disability comprises both "impaired intelligence…. [and] impaired social functioning… which [start] before adulthood with a lasting effect on development". It is sometimes used interchangeably with the terms learning difficulty, developmental disability, intellectual disability and mental handicap. The British Institute for Learning Disabilities (BILD 2007b, webpage) suggests that:

> *"Learning disabilities can be a useful term …that… indicates an overall impairment of intellect and function [whereas] learning difficulties should be used to refer to specific problems with learning in children that might arise as a result of issues such as medical problems, emotional problems, and language impairments".*

Historically, professionals working in field of learning disability have used Intelligence Quotient (IQ) as a system of diagnosing a patient's learning disability. Classifications of diagnosis range, traditionally, from mild/moderate to profound across a spectrum of IQ scores and are often used to plan and deliver services. This, however, is the subject of some controversy; on one hand, it can help to recognise patients who require additional support and can be useful to support mainstream health staff to appreciate diversity (Corbett 2007). On the other hand this system of 'labelling' is thought to grade learning disabilities (Gillman et al 2000) and some service users do not favour it as an approach. Consequently, there appears to be a general move away from the use of IQ alone in the identification of the presence of a learning disability and a move towards incorporating assessment of social functioning and communication skills.

It is difficult to establish exactly how many people have a learning disability due to the complex nature of its diagnosis (not all cases of mild learning disabilities are even diagnosed) and also due to the fact that not all people with learning disabilities use formal services. Valuing People (DOH 2001) indicated that there are 210,000 people with severe learning disability and a further 1.2 million with a mild or moderate learning disability living in England. Before "A life like no other" (Commission for Healthcare Audit and Inspection 2007), a national overview of the services for people with learning disabilities did not exist and local / regional statistics were inconsistent. Some services collate and operate learning disabilities registers, but these need to be maintained and updated in order to ensure accuracy and are dependent on service users giving their permission to being included on such lists. Prevalence rates of learning disabilities range from source to source; BILD (2007b) estimate that between 1 and 2 percent of the population has a learning disability, whereas Whittaker (2004) suggests the national average to be 0.23 to 0.29 percent. In one study of a GP's caseload of two thousand patients, forty patients were noted as having learning disabilities, of which eight had severe learning disabilities and the remainder had mild / moderate disabilities (DOH 1999).

A process of deinstitutionalisation, that began in the 1970s and continued into the 1990s, involved the movement of people with learning disabilities from dedicated inpatient hospitals into community based residential settings (Ruddick 2005). This led to an increase in demand for primary and secondary health care services for this group of people. Every year approximately 26 percent of people with learning disabilities are admitted to acute hospital trusts; this compares to 14 percent of the general population (Mencap 1998). Lennox et al (2003) attempted to identify the profile of people with learning disabilities using healthcare services; their study revealed that people living in supported or supervised care settings were more likely to access healthcare, and women accessed services more readily than men.

We know that people with learning disabilities can be more prone a number of medical conditions including epilepsy, dental problems, hypertension and respiratory problems (FPLD 2006). The Department of Health's "The Healthy Way" (DOH 1998) document attempted to address this issue nationally by targeting healthcare provision for people with learning disabilities towards four key target areas: heart disease/stroke, cancer, mental illness and accidents. Locally, data collected by the hospital's Information Development Team (2007) indicates the most common diagnoses of patients (in 2005/06 and 2006/7) with a co-morbidity of learning disabilities include dental, neurology and cardio-thoracic problems.

Having established that people with learning disabilities can have a greater need for healthcare, it is also recognised that they can have significantly poorer health outcomes (WHO 2001). Reasons for this cross the boundaries of primary and secondary care and include lack of empowerment, support and understanding for service users regarding when and how to access healthcare services. In 2004, Mencap published "Treat me right!" stating that, despite existing legislation and policy, people with learning disabilities continued to have worse health than other people attributable to lack of access to necessary services and

treatment. As a vulnerable group of patients, it has also been identified that they may be more at risk of things going wrong when using general hospitals than the general population (NPSA 2004).

1.3 PROJECT DRIVERS

The number of legislative and best practice guidelines regarding the rights of people with learning disabilities and the duty of service providers to promote equal access initially appears limited. However, on closer inspection the duty of health and social care providers becomes overwhelmingly apparent and is clearly stipulated. The following information gives a chronological overview of the predominant guidelines highlighting the responsibility of organisations when providing services to people with learning disabilities

"Better services for the mentally handicapped" (HMSO, 1971) was one of the first white papers that specifically identified the need for dedicated services for people with learning disabilities. In the light of considerable media coverage at the time of the appalling conditions in (so-called) care institutions for people with learning disabilities, the paper outlined details for making improvements. Despite this, recognition that specialist skills were required by members of staff dedicated to working with people with learning disabilities was not acknowledged formally until the "Jay Committee Report" in 1978, which also noted in its long list of recommendations that people with learning disabilities have the right to a good quality of life.

Throughout the 1980s there appears to be a notable gap in the development of policy promoting accessible and appropriate services for people with learning disabilities. This is particularly surprising when it is considered that a major shift was taking place in the structuring of health and social care provision for people with learning disabilities. A process of deinstitutionalisation involved a shift in the delivery of care from learning disability hospitals to community settings.

Then, in 1990, the “NHS and Community Care Act” (OPSI, 1990) was introduced, stating that healthcare services should be provided on the basis of assessed need. As has already been noted, people with learning disabilities have a higher rate of predisposal to poorer health. It is consequently suggested that a greater representation of needs of people with learning disabilities is required when planning services, particularly as “too often treatable illness is undetected until it has progressed to a stage where treatment is less effective” (Department of Health 1995, page 14).

The “Disability Discrimination Act” (OPSI 1995) stipulates that it is the duty of public sector organisations to promote equality amongst its service users. The Act was later amended (in 2005) to legislate that organisations must make provisions regarding access to information and services, including of course, healthcare assessment, treatment and information. This was a key driver for all service improvement initiatives for people with disabilities, including those with learning disabilities. The “European Human Rights Act” (Department for Constitutional Affairs, 1998) echoes the essence of the DDA in some of its sixteen basic human rights, for example the right not to be subjected to inhuman or degrading treatment (Article 3) and the right to freedom from discrimination (Article 14) and therefore to receive equal treatment.

A report by Mencap, “The NHS: Health for all?” (Mencap 1998), revealed in detail problems that people with learning disabilities encountered when accessing healthcare services and the quality of services that they received. The Department of Health responded to this by launching “Signposts for Success” (DOH 1998a) which offered “an extensive blueprint for the strategic development of services for people with a learning disability” (Parish and Kay 1998, page 478). The Department of Health simultaneously produced “The Healthy Way: How to stay healthy a guide for people with learning disabilities” (DOH 1998b); this was notable because it was the first strategic document to be developed in consultation with service users.

A turning point in policy concerning people with learning disabilities was the launch of the key document “Valuing People; A new strategy for learning disability for the 21st Century” (DOH 2001). It was the first White Paper to be written specifically for people with learning disabilities in over 30 years (Care Services Improvement Partnership 2007). Its ultimate aim was to provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities. The “NHS Improvement Plan” (DOH, 2004a) went on to prescribe that the focus of NHS Trusts should be to prioritise the needs of patients and other service users by providing personalised care responsive to individual needs. In order to ensure equity across the NHS as a whole, a standards-based system was generated and in April 2005 (after a consultation and preparation period), “Standards for Better Health” (DOH 2004c) became effective. It sets out a performance framework for NHS Trusts, comprising core and developmental standards that “should be interpreted in a way that challenges discrimination” (page 4) and “promotes equality of access to services…..for all members of the population” (page 15).

In 2004, Mencap published “Treat me right!” stating that, despite existing legislation and policy, people with learning disabilities continued to experience difficulties in accessing services and treatment. “You can make a difference” was a guide produced by the Disability Rights Commission (DOH 2004d) providing guidance for frontline hospital staff to improve services for people with learning disabilities.

Mencap called for change in legislation to protect vulnerable people and in 2005 the “Mental Capacity Act” (OPSI 2005) was passed by Parliament. It provided a legal framework for people who do not have capacity to make decisions, and prescribed relevant organisations to implement local policies regarding the safeguarding of vulnerable adults. Consent to treatment is a significant element of safeguarding adults and service users (or their next of kin if they do not have the capacity to make decisions) need to have access to appropriate communication and information in order to make informed decisions about their health and

health services. The Litigation Authority's "Risk Management Standards" (NHSLA 2006) provide a framework (superseding in most cases the "Clinical Negligence Scheme for Trusts" and the "Risk Pooling Scheme for Trusts") for managing clinical risk which includes consent-gaining and its relation to patient information.

Although steps are being taken in the right direction regarding policy, a shocking report by Mencap, "Death by Indifference" (2007), reveals that the practical consequences of not improving services for people with learning disabilities can be fatal. The Disability Rights Commission (2006) carried out a formal investigation into health inequalities that people with disabilities face, and their report entitled "Equal Treatment: Closing the Gap" noted that improving access is "crucially dependent on enforcement" (page 2) in order to provide the necessary protection from any potential complacency of those providing services to people with learning disabilities.

1.4 INVOLVING SERVICE USERS

Engaging patients, carers and the public in shaping the NHS and their personal experiences of care is a core element of the NHS plan (DOH 2000b). The Commission for Patient and Public Involvement in Health (CIPPH) was established in January 2003 and legislated that service users must be involved in decision making about health and health services. "Patient and Public Involvement in Health: The evidence for policy implementation" (DOH 2004b) notes that involvement activities lead to increased patient satisfaction and outcomes amongst other benefits. It also states that public collaboration is an effective route to building community relationships and highlights the importance of involvement of "all members of the local community". However, obtaining the views and opinions of patients and the public and transforming these into meaningful products can be challenging. Involving patients with learning disabilities in service development is highlighted as a major recommendation of Valuing People (DOH 2001). In fact the national self advocate advisory group entitled their contribution

to the Valuing People white paper “Nothing about us without us” (IAHSPLDP, 2003), which highlights the key concept that people with learning disabilities should, and want to, be at the heart of service planning and development.

1.5 HEALTH ACTION PLANS

One of the key recommendations of the Valuing People strategy was the introduction of Health Action Plans (HAPs) which aimed support the provision and coordination of better services to improve the health and general well-being of people with learning disabilities. HAPs provide information about the person’s health and health choices and are intended to be used a resource for both the person themselves and healthcare providers, who, by reading the document, can gain an insight into the person’s physical, cognitive, sensory, social and emotional care needs. HAPs co-exist with health facilitation, which is person-centred support, advice and advocacy provided by health or social care staff.

It was intended that HAPs would have been completed, implemented and integrated into health service culture by now, but they are proving to be exceedingly complex documents. Even though a period of transition was predicted (DOH 2002), the task of completing one with/for every person with learning disabilities is proving to be quite challenging for community services. HAPs require considerable focus, accuracy and time applied to them if they are to become useful and useable resources. Some primary care trusts are now in the process of establishing posts (usually fixed term) in order that dedicated staff will be responsible for the completion of HAPs. As an interim measure, some services, such as a Learning Disability Team in Gloucestershire (described by Corbett 2007, pages 107 to 110) have developed “Hospital Passports” for implementation as patient-held communication tools. Ultimately these will form part of patients’ HAPs, when they have been completed (possibly as an appendix) but they have also been designed as stand alone documents. Design and implementation of passports needs to be carried out locally in partnership with service users and community learning disability

advocacy groups to ensure that the documents communicate issues that service users consider as important.

1.6 PROJECT PURPOSE

The definite and pressing need to improve access to acute healthcare for people with learning disabilities has been established and in response, this project looked at a way that this might be achieved. The use of the passports by people with learning disabilities when using inpatient services (i.e. when being admitted to hospital) was implemented in conjunction with training to inform staff about how to use them. The project longitudinally measured staff opinion and perception about the most significant challenges, problems and issues that present when working with people with learning disabilities in an acute setting. The nominal group technique was used to identify consensus opinion comparatively before and after the implementation of the passports. Patients' experiences were also evaluated to investigate whether the passport made a difference from a service user's perspective.

1.7 PROJECT AIMS

The aims of the project fall into three categories that Thomas (2000) specifies as being essential considerations in a doctoral project:

1.7.1 Addressing gaps in the knowledge

It is known from previous project work carried out locally, such as the learning disability project work that formed part of this Doctoral programme (Glaysher 2005), and from national and international evidence that people with learning disabilities experience difficultly in accessing services. This project intended to address some of the gaps in the knowledge regarding an approach to developing staff awareness of the complex needs of people with learning disabilities when using acute healthcare services.

It is pertinent to the work and timescale of the project that the Independent Inquiry into Access into Healthcare for People with Learning Disabilities is underway. The inquiry is intending to report its findings in

late July 2008 (coinciding with the submission of this project); it will identify the action needed to ensure adults and children with learning disabilities receive appropriate treatment in acute medical (hospital) care and general primary care (IAHPLD 2007).

1.7.2 Meeting the needs of a sector of service users

To establish a context for the project, we can turn to service user statistics. Estimates of the number of people who have a learning disability range from 0.23% (Whittaker 2004) to 2% (BILD 2007b) and 26% of this patient group are admitted to hospital every year (Mencap 1998). Local data reveal that in one year (2006-7) the hospital treated 415 adult inpatients with a learning disability (Information Development Team 2007). This is a small but significant number of service users and anecdotal evidence from the Complaints and Improvements Department[1] shows that from this population of service users, there were a number of reported concerns and poor experiences of using acute health services. The needs of people with learning disabilities are cannot be overlooked due to the potential impact on health outcomes. Mencap's "Death by Indifference" (2007) outlined six cases in which service users with learning disabilities had died due to insufficient and inadequate healthcare and therefore the lessons learnt from these cases must be disseminated throughout all healthcare organisations.

1.7.3 Identifying implications for practice

The transferability of the project findings was a major factor in selecting and planning this project. Previous work in the hospital to improve the experience for people with learning disabilities (Glaysher 2005) involved working with a local organisation that supports people with learning disabilities. Members of that organisation frequently used an expression "to get things right for people with learning disabilities is to get things right for a lot of people". This adage succinctly outlines the transferability of the

[1] Anecdotal evidence only is available as the term "learning disability" is not recorded as a code to/from which data can be linked in the hospital's corporate and risk management data systems. More detailed information is provided in the Methodology (Chapter 3).

project outcomes because by improving access to healthcare for a minority group, such as people with learning disabilities, access can be improved for other minority groups including service users with other disabilities and people who do not speak English as a first language. Additional transferability of the findings includes the scope to roll out the findings to other settings such as other healthcare organisations; the potential spread of the findings is discussed in more detail in the Discussion and Conclusion chapters.

1.8 CHAPTER SUMMARY

It can be concluded that major changes are required in the way that healthcare is provided for people with learning disabilities. Involving service users in the way that services are planned and delivered, and using communication tools such as hospital passports, are two key concepts anticipated to improve patients' experiences and health outcomes. There is little evidence to date however, that demonstrates the effect that these can have on staff awareness levels of patients' physical, cognitive, sensory, social and emotional care needs. It is essential that staff understand patients' needs more clearly so they will be able to better respond and deliver more responsive, effective care. This project intends to contribute to the current dialogue regarding improving access for people with learning disabilities to mainstream health services, by aiming to address some of the gaps in the knowledge regarding an approach to developing staff awareness of the complex needs of people with learning disabilities when using acute healthcare services.

CHAPTER 2

LITERATURE REVIEW

2.1 SEARCH STRATEGY

A detailed overview of the search strategy applied to the literature and other evidence is provided in Appendix M1. The majority of the secondary data collection was conducted October 2006 to October 2007 (see Project Timeline, Appendix M5) though, of course, relating to the evidence base was a continual component of the project.

2.2 ACCESS TO HEALTHCARE

In order to identify and address factors that affect access to healthcare, it is first useful to decide upon a definition or conception of the term 'access'. McNally and Alborz 2004 suggest that the major dimensions of access can be defined as the identification of need, organisation of healthcare, entry access (to primary healthcare for example) and continuing access (to secondary or further healthcare). Access for people with learning disabilities is explored in more detail by Sowney and Barr (2004). The authors undertook a concept analysis of 'equity of access' using a framework proposed by Walker and Avant (1995, cited in Sowney and Barr 2004: p 251). The aim of the analysis was to provide healthcare professionals, people with learning disabilities and their carers clarity and understanding of the much used concept. 'Equity of access' can be considered (in sum) as fairness for those seeking, entering and using healthcare. Of particular value to this project, are the empirical referents (p: 259) suggested by the authors as a way of measuring and evaluating equity of access, which include:

- interviewing people with learning disabilities regarding their satisfaction having used healthcare services
- interviewing healthcare professionals about their learning needs regarding care provision for learning disabled patients
- examining policies and protocols to establish the inclusivity of healthcare services.

These referents helped to inform the choice of three of the methods used in this project, namely the patient experience evaluation, the nominal groups with staff and the organisational review.

2.3 ACCESS TO HEALTHCARE FOR PEOPLE WITH LEARNING DISABILITIES

Investigating the premise that people with learning disabilities experience barriers in accessing healthcare is key to establishing the nature of reduced health outcomes and to gaining an insight into ways to address them. Useful foundations for understanding this premise are provided in the form of several review articles, such as Ruddick 2005, Hogg 2001 and Brown 2005 and an additional practice education paper (Godsell and Scarborough, 2006). However, perhaps the most thorough search of literature was a systematic review conducted by National Primary Care Research and Development Centre, Manchester University (Alborz and McNally 2004, McNally and Alborz 2004, Alborz, McNally and Glendinning 2005). The authors applied a three-tiered methodological approach to searching electronic databases, inviting evidence from consultations with key individuals/organisations and a mail shot to experts and researchers (though how/why these individuals were identified was not communicated). Eighty-two articles were evaluated (short-listed from an original 2221 articles) and using an existing conceptual framework (the Access to Health Care model, Gulliford et al, p: 175 in Alborz et al 2005) a number of factors affecting access to healthcare were identified. The primary aim of the review was to identify practice implications for healthcare librarians regarding an approach to the literature and therefore the time and resources required for this profoundly in-depth methodological approach go far beyond the scope of this project. Its findings are of benefit, though, both to this project and of course to the wider context of an evidence base regarding access to healthcare for people with learning disabilities. The findings of the review have been presented in Table 1 alongside additional barriers to healthcare identified in the four other comprehensive review articles noted above. These have in turn informed the subsequent sections of this literature review, regarding the perceptions and experiences of service users with learning disabilities and healthcare staff as well as initiatives to improve access.

It is notable that the subject of access specifically to acute healthcare services for people with learning disabilities is not covered extensively in

the literature. The majority of the literature searched for this review was published in the last 13 years which perhaps shows a general response to the legislative drivers regarding equity of access for people with disabilities (since the Disability Discrimination Act (DOH 1995)) and practice guidelines regarding care provision for people with learning disabilities (see Chapter 1).

2.4 PERCEPTIONS AND EXPERIENCES OF SERVICE USERS WITH LEARNING DISABILITIES

Ten years ago Hart (1998) stated that the experiences of people with learning disability regarding general hospital remained relatively unresearched. This statement appears to remain relevant; only five studies since were identified for this literature review involving consultation with service users themselves. Of these, four related to experiences of general, secondary or acute healthcare. Due to the fact that such a small empirical and evidential base exists, these studies have been outlined individually in the following section; conclusions have been drawn at the end regarding the choices of methodology and method that have contributed to the decisions made regarding this project.

In response to her observation, Hart (1998) conducted thirteen interviews with people with learning disabilities. Unfortunately, the actual sampling methodology used in the study is unclear ("respondents were made known to the author by service managers", p: 471) though the reader is advised that all participants had received inpatient, outpatient or day-case treatment within the last three years at a general hospital. Patients identified feelings of fear of receiving treatment, experiencing ineffective communication by staff (such as using jargon or an inability to provide an explanation in comprehensible terms) and unhelpfulness of staff towards their needs. Participants felt many of these were attributable to a lack of understanding regarding learning disabilities. A grounded theory approach was professed, but in the absence of information about the interview or transcript analysis methods, it is difficult to ascertain how the process of constant comparative analysis (an identifying component of grounded theory, Dick 2005) led to the emergence of the outcomes.

Table 1: Barriers to healthcare identified in reviews of the literature

Identification of health needs • difficulty or inability to identify health need by person with learning disabilities [1] • difficulty or inability to identify health need by carer of person with learning disabilities [1] • person with learning disabilities or their carer not seeking healthcare even when health need identified [1]
Organisational barriers • shortage in specialist services [1] • restrictive or inaccessible physical environment (such as poor signage and busy atmosphere) [1],[4], [5] • inappropriate means of contacting people (such as inaccessible appointment letters) impairing uptake of services [1] • confusion regarding interface between mental health and learning disability services [1] • time constraints [1] / lack of adequate consultation or assessment time [3] • people with learning disabilities feel their complaints are not taken seriously [1]
Skills/competence of healthcare professionals • lack of interpersonal skills of healthcare professionals resulting in person with learning disabilities not feeling heard or taken seriously [1] • have bias and make assumptions about people with learning disabilities [5] • self-identified lack of knowledge of learning disabilities among healthcare professionals [3] • insufficient specialist support available to staff working in general healthcare settings [1] • difficulty identifying signs of health problems in person with learning disability (i.e. picking up on behavioural changes) [2] • over-reliance on untrained / informal carers for information [2] • lack of awareness of policy and good practice guidelines for assessing and treating people with learning disabilities [3] • lack of undergraduate and continuing education for medical and healthcare professionals [3] • inexperience or inability to apply alternative methods of communication [5]
Presentation of learning disabled person • challenging behaviour [3], [4] • limited understanding [5] • expressive and receptive communication difficulties [3] including additional sensory impairments that affect ability to hear and process information [5] • difficulty or inability to following written instructions or understand written information [4], [5] • lack of preparation of learning disabled person for medical appointment / treatment [3] • previous poor experience of healthcare [5]

Source: [1] Alborz et al (2005), [2] Ruddick (2005), [3] Hogg (2001), [4] Brown 2005) and [5] Godsell and Scarborough (2006)

The perception by service users of an inadequate skill set among staff in acute settings was supported by the findings of two consensus development conferences conducted by Cumella and Martin (2004). The authors identify that their choice of method does not generate information that can be readily generalised about the experiences of people with learning disabilities nor do they lay claim to the effectiveness of their recommendations. Instead they set out to generate a broad range of reported experiences of using general hospitals and therefore adopted a purposive sampling methodology, inviting individuals recommended by learning disability services. The consensus of people with learning disabilities and their carers was that staff often seemed embarrassed or reluctant to talk directly to learning disabled patients and were unapproachable when help was needed. Other outcomes included the consensus that information for people with learning disabilities about admission, discharge and waiting times was usually unavailable or inadequate / inaccessible. Services users stated that being ill-informed created feelings of fear and anxiety about using hospitals but also of becoming unwell in the future.

Ineffective communication and fear of using hospital services were once more reiterated as the most pertinent barriers to accessing secondary healthcare in the findings of a study by Scott, Wharton and Hames (2005). This study involved learning disabled participants aged between 16 and 19 and therefore demonstrated commonalities between the experiences of both adult and child patients. The authors selected semi structured focus group interviews for data collection as they felt this approach would not discriminate against those who cannot read or write or those who might need questions and statements re-phrased. Communication issues associated with negative experiences of using hospital services included not being told what was going to happen before, during or after an appointment or admission, particularly with regards to waiting times. All fourteen participants relayed feelings of fear related to visiting hospital, mainly associated with feelings of uncertainty but also due to having to enter an unsettling physical environment. The authors state that a limitation of their work was that it did not commence

with a pilot study, which could have determined the usefulness of responses likely to be yielded. Another possible limitation could be perceived as the overlap in data collection methods; one two-hour focus group in which the participants were interviewed using semi structured questions. Whilst they justify their choice of method, it is hard to perceive how the findings were then analysed and unfortunately this is not conveyed to the reader. However, as this was apparently the first study to investigate the experiences of young learning disabled people using acute hospital services, the findings undisputedly contribute to the knowledge base regarding service user perceptions of healthcare services.

In contrast to the rather negative experiences outlined above of general hospital services, users' experiences of primary healthcare were found to be generally positive by Martin, Roy, Wells and Lewis (1997). In this large, multifaceted study, the authors gathered the views of one hundred and four informal carers via questionnaire, thirty one service users through focus groups and a further fifty three service users through exit polls following a primary care appointment. On issues of communication, the carers gave significantly positive responses; for example 96% of respondents felt that the doctor spoke in a way that could be understood and 83% stated that the doctor allowed the person with learning disabilities to speak for themselves. This was reflected by the service users in the exit polls, 81% of whom responded that they liked seeing the doctor. Perhaps these positive perspectives could be attributable to the fact that GPs perceive themselves as the most appropriate people to provide healthcare to people with learning disabilities (Stein 2000, Dovey and Webb 2000). The usefulness of Martin et al's (1997) study could perhaps have been enhanced by clearer presentation of the findings; the different research strands have been separately reported and therefore have not taken advantage of the opportunities offered by a triangulative approach to using mixed methods.

Despite the diverse range of research methodologies used in the studies researching this area, communication issues were consistently cited as

the most significant barriers to accessing services. However, as such a small base of literature exists about learning disabled peoples' experiences of using healthcare services in England, is difficult to draw conclusions that will inform the choice of methodology/methods for this project. Interviews, consensus development conferences, semi-structured focus group interviews, questionnaires, and exit polls were all used by the authors but perhaps the most important consideration would be the flexibility or adaptability of the data collection tool. Due to the nature of learning disabilities, it is essential that researchers are not bound by rigid methods and have the opportunity to communicate in a way with which the service user is comfortable in order to gain as much insight into their experiences/perceptions as possible. Another important lesson highlighted is the importance of clear presentation of methodological information as a well as results, which appears to be a particular challenge in mixed method studies.

2.5 PERCEPTIONS AND EXPERIENCES OF HEALTH CARE PROFESSIONALS

The research carried out to date regarding the perceptions of healthcare staff about learning disabilities seems to fall into two main categories: attitudes of staff and their ability to communicate. Interestingly, the first appears to have been investigated using a range of quantitative, qualitative and mixed-method approaches. On the other hand, issues of communication have been explored and captured using qualitative methodologies.

The effect that previous experience or contact with people with learning disabilities has been identified has having an affect on the attitudes of healthcare professionals. In apparently the earliest study to investigate attitudes of healthcare staff towards people with learning disabilities, Slevin and Sines (1996) explain that attitudes affect our emotions, value base and behaviour. The authors applied a triangulative approach by using the validated Attitude Towards Disabled Persons scale (Yuker et al 1966, in Slevin and Sines 1996) as well as semi-structured interviews. It

was found, from the sample of 31 staff that completed the questionnaire from which 10 went on to take part in the interviews, that nurses in a general hospital possessed a negative attitude towards patients with learning disabilities. More positive attitudes were found to be held by graduate nurses and nurses who had had more contact with people with learning disabilities. This resonates with one of Sowney and Barr's (2005) focus group outcomes that nurses with pre-registration experience of caring for people with learning disabilities perceived themselves as being more competent in working with this group of patients. The effect of contact with people with learning disabilities was also one of the variables investigated by McConkey and Truesdale (2000) in their study of the attitudes of health care staff. A questionnaire, previously validated by one of the authors, was completed by 1008 participants comprising from specialist learning disability settings (28%), nurses (28%) and therapists (17%) working in general hospitals and university students representing a non-staff group (27%). The authors report that, as expected, nurses and therapists working in general hospitals had more experience or contact with learning disabled people than the non-staff group. However they also had lower levels of confidence when caring for patients with learning disabilities, compared to patients with other types of disabilities. One of the major limitations of Slevin and Sines (1996) work was the potential generalisability of the findings due to the small scale of the study (31 nurses). However, as McConkey and Truesdale (2000) generated similar findings regarding professional attitudes from their large scale study (with 1008 participants), it appears that the validated questionnaires used in these studies were well selected for producing representative findings.

Accident and Emergency nurses taking part in Sowney and Barr's (2005 and 2007) focus groups reported that despite having no previous experience or education of learning disabilities, they needed to care for such patients presenting at A&E. The focus groups, conducted in five hospitals in Northern Ireland, usefully generated issues that may not have been revealed by other more rigid data collection tools, for example the identification by staff of fear and vulnerability in their role as care providers. Some of the participants expressed concerns about causing

offence or making a patient feel more uncomfortable or distressed due to lack of knowledge about learning disability. Hastings and Remington (1994) support this possibility, observing that ineffective staff behaviour towards a patient could be counter-habilitative and could even trigger challenging behaviour in that patient. Although these findings emerged from a small study in a social care setting, there is scope for some generalisation for hospital care providers.

The ability of care providers to communicate is an essential part of healthcare assessment and treatment planning and delivery. It is central to an effective therapeutic relationship and to achieving optimal outcomes in health and quality of experience. If the patient has learning disabilities, this can pose considerable challenges for healthcare professionals. Phenomenological methodologies have been twice been employed, using very different methods, to investigate this. Firstly, general hospital staff at Cumella and Martin's (2004) consensus development conference identified that effective care of people with learning disabilities was impeded by lack of information from primary and specialist care staff. This highlights that a particular benefits of using a consensus development approach is that it captures a wide range of sometimes unpredictable findings; Cumella and Martin (2004) state that it is a method capable of generating one of the widest range of views though its findings ideally benefit from being strengthened by a sound epidemiological base and studies investigating the efficacy of initiatives. Secondly, in a study by Purcell, Morris and McConkey (1999) it was found that staff perceptions of learning disabled patients' communication competence varied from their actual communication ability. In a small-scale observational study conducted in social care settings, comparisons were made between staff ratings of their client's communication and the results of standardised assessments conducted by experienced speech and language therapists. The complex results are clearly summarised by the authors who report, among other things, that staff tended to overestimate a client's ability to understand. This study involved self selected participants who knew their clients well, which suggests that the divide between actual and perceived communication is even greater if the

member of staff does not know the patient (such as when a patient is admitted to a general hospital). The gap between perceived and actual communication ability of a learning disabled patient highlights one of the most critical elements of healthcare communication: the process of gaining consent. Healthcare staff are very wary of "the increasingly litigious atmosphere in healthcare" (Cumella and Martin 2004 p:36) and uncertainty has been identified, in particular, regarding a patient's ability to give consent and the guidelines in place to govern this process (Sowney and Barr 2007).

The knowledge base about the perceptions and experiences of health care professionals when working with patients with learning disabilities shows that experience and education essentially contribute to professional knowledge and confidence. This in turn leads to competence in communication which is an essential element of healthcare provision particularly with regards to gaining consent.

2.6 IMPROVING ACCESS TO HEALTHCARE FOR PEOPLE WITH LEARNING DISABILITIES

Of the limited evidence base regarding access to healthcare for people with learning disabilities, the majority of literature considers ways in which it can be improved and ranges from theoretical suggestions to empirically evaluated initiatives.

Health screening has been identified through a number of sources to have a positive impact on the uptake of services and on consequent health outcomes. In the largest study of its type, Webb and Rogers (1999) found that of the 1311 learning disabled people who received health screening in a primary care setting, 73% required follow-up healthcare interventions. Similarly, in a multi-method health screening project Martin, Roy and Wells (1997) picked up previously undetected medical problems in 83.5% of people with learning disabilities. Over-looked medical conditions in people with learning disabilities were also identified in a meta-analytic study looking at the case records of 589

people with learning disabilities (Kerr, McCullock, Oliver et al 2003). In all three studies, communication difficulties during consultations were noted as the major factor affecting the ability of healthcare professionals to conduct assessments and detect underlying medical conditions. It is important to acknowledge the contribution that screening can make to the broader picture of improving access for this group of service users, but as screening is usually delivered in primary or preventative care settings, it is beyond the remit and boundaries of this project. Attention has been paid, therefore, to initiatives that can be adapted for an acute care setting.

Staff training and education is addressed by several sources, particularly as it appears to be limited or lacking in the professional training of doctors, nurses and other members of the healthcare team (Brown 2005, Dovey and Webb 2000). Initiatives have included continuing professional development and post graduate education. The focus of a study by McMurray and Beebee (2007) was the effectiveness of staff awareness training days about learning disabilities. The ninety-two attendees were followed up after a month by postal questionnaire and the forty-six responders indicated that the training had raised awareness of learning disabilities, how to contact specialist support services and issues of capacity to consent to treatment. It was felt that input of service users on the training sessions was very important; a stance that supported the findings of Glaysher's (2005) mixed-method approach to a review of general hospital services by users with learning disabilities (this work formed part of this doctoral programme). The views of service users who had rated hospital information, the hospital site / environment and clinical care were presented to 170 staff through a series of presentations by a learning disability drama company. Maximum scores for usefulness of the training were given by 83% of attendees of the presentations, but unfortunately the long term impact of staff education, such as changes in attitude and practice, was not measured.

Several studies have looked at the use of tools to aid communication between healthcare professionals and people with learning disabilities, though overall conclusive evidence of an effective approach has yet to be

produced. In Kerr, McCullock, Oliver et al's (2003) study involving a case note review of the learning disabled patients of a primary care practice, a small number (10%) of the patients were given written reports summarising the findings of the review and recommendations for healthy living. These were not, however, provided in an accessible format and therefore, despite anecdotal written evidence from the carers suggesting that they were useful, their value to learning disabled service user remains to be established. A randomised control trial conducted across five general practices in Wales, Jones and Kerr (1997) found that inserting cards to prompt general practitioners regarding communication in their assessment of people with learning disabilities did not affect consultation patterns, referrals to specialist services or clinical outcomes. Dodd and Brunker (1999) looked at the usefulness of a pictorial communication aid entitled "Feeling Poorly?" used in appointments at a GP surgery. The authors suggest that the aids improved learning disabled patients understanding of their health and health problems, but no statistical analysis was conducted and findings were generally inconclusive due to the small sample size (10 patients). In Scotland, "Health Logs" were used in one setting to "assist the individual with complex communication difficulties to achieve improvements in health and well being …[and] provide good information for healthcare professionals" (Curtice 2002). Although positive feedback about the usefulness of the logs was outlined, the author omits to inform the reader of how this was collated or about the sample size / methodology. The implementation of Health Action Plans as information / communication tools for both people with learning disabilities and healthcare professionals is still very recent (and pending). Articles describing the design of HAPs (Hunt, Rankine and Blackmore, 2006) and their experimental implementation (Howatson, 2005) have been identified, but empirical evidence of their effectiveness is, as yet, unavailable.

Other suggestions for improving access to and experience of acute healthcare for people with learning disabilities include having dedicated or specialist support staff (Davis and Marsden 2001), applying a person-centred approach to planning care for individual patients (Hunt et al

2004), and preparing patients for hospital with videos or pre-admission tours (Cumella and Martin 2004 and Corbett 2007). With reference to all of these though, reliable empirical evidence is awaited regarding their effectiveness.

2.7 CHAPTER SUMMARY

There is not a vast evidence base relating to the use of general hospital services by people with learning disabilities, either from the perspective of the service user or the service provider. Several review articles provided the grounding for this literature review, outlining the barriers to access that people with learning disabilities face. Perceptions of people with learning disabilities have been captured by a variety of methods including questionnaire, interview, focus groups, consensus development conferences and exit polls. Researchers working in this area need to address difficulties that can present when working with service users with learning disabilities including, for example, the suggestion that individuals can be vulnerable to suggestions and peer pressure (Martin et al 1997). Therefore, particular attention must be paid when designing research aiming to capture service user perspectives and this indicates the use of techniques that enable the researcher to communicate with the service user in the most accessible, ethical way.

There is, similarly, a dearth of literature about the perspectives of healthcare providers; the literature addressed, in the main, attitudes of staff and the effect that experience and education of learning disabilities has on the ability / confidence of the care provider. Little appears to be known about the effectiveness of specific awareness-raising initiatives over time and whether they have an effect on the quality of experience of the service user. In addition, there has been a call for research that is underpinned by a sound epidemiological base (Cumella and Martin 2004), suggesting that future research should investigate the prevalence of learning disabilities in order to provide justification for the research itself.

To tie all of these points together, a gap exists in the evidence base regarding an approach to developing general hospital staff awareness of learning disabilities when using acute healthcare services that longitudinally measures changes staff attitudes or awareness and the effect that this has on patient experience. The need for this research to be strengthened by an epidemiological base and also by the use of mixed methods is also recognised. Such research will contribute to the currently small but growing dialogue regarding improving access for people with learning disabilities to healthcare services.

CHAPTER 3

METHODOLOGY

3.1 PROJECT QUESTIONS

The project set out to answer the following questions:

- What were the challenges that staff identified when working with people with learning disabilities (at the start of the project)?
- Can the use of hospital passports improve the patient experience?
- Can hospital passports increase the awareness of staff in an acute setting caring for people with learning disabilities?

3.2 PROJECT OBJECTIVES

The project objectives were:

- To conduct a literature review and gather a wider evidence base regarding issues of and barriers to access to healthcare for people with learning disabilities.
- To establish baseline data about service users with learning disabilities using the hospital services, to provide a profile of learning disabled service and enable comparison with the wider population of service users.
- To carry out an overarching organisational review of policies, processes, roles and responsibilities in place in the hospital regarding the care of people with learning disabilities.
- To measure consensus of opinion among staff regarding the challenges faced when working with patients with learning disabilities.
- To design and implement a hospital passport with and for patients with learning disabilities, for use as a communication tool when using hospital services.
- To train staff to recognise and effectively use the hospital passports when providing care to a patient with learning disabilities.
- To re-measure after six months consensus of opinion of staff to find out if their awareness of learning disabilities improved as a result of working with patients using the hospital passports.

- To evaluate patient experiences of using the hospital passport during an admission using semi structured questions.
- To embed reflexivity in the project as much as possible in order to demonstrate an awareness of firstly the effect of the involvement of the researcher on the project process and outcomes, and secondly the implications of the epistemological selections made.

3.3 PROJECT IMPLEMENTATION

3.3.1 The project overview team

The project was overseen by an interagency, multidisciplinary team who met bi-monthly (and communicated by email and telephone between meetings when necessary). The project overview core team comprised members of staff at the hospital with a special interest in learning disabilities and learning disability healthcare professionals based in the community. It was also underpinned by service user involvement. Details of the team can be found in Appendix M1.1.

3.3.2 The role of the researcher

My role in the project started with the conception of the project idea and has continued with the planning and execution of the project (see Appendix M1.2 for details).

3.3.3 Identification of stakeholders

Giving consideration to individuals who could benefit from the project work, support it and disseminate it is described as an essential step in the diagnostic analysis of a project (NHS Centre for Reviews and Dissemination, 1999), which is recommended for the successful implementation of evidence into practice. Project stakeholders have been outlined in Appendix M.1.3.

3.4 PROJECT DESIGN

The project employs a combined approach; it aims to look at, interpret and improve practice, actions and experiences within an organisation.

The reason for selecting a combined approach was initially driven by the choice to use a consensus gathering approach to collating information about staff awareness (this is discussed in more detail later in this chapter under The Planning Stage), and the need to support the findings with quantitative data. This was an almost back to front process in which the methods of data collection informed the project design rather than the other way around Eachus (2006).

The advantages and disadvantages of combined research are readily discussed in the literature (Golafshani 2003, Bowling 1997, Pope and Mays 1995 and 1996, Begley 1996 to name but a few). Both qualitative and quantitative methodological approaches have strengths and weakness and therefore can complement each other (Polgar and Thomas, 1995) and can strengthen the findings of a project (Olson, 2004). The qualitative components of the research design offer naturalism, or the ability to study people in their own setting (in the case of this project the staff providing care in an acute hospital). The qualitative findings can be strengthened by numerical data (such as the descriptive statistical data about service users and the ratings generated in the nominal groups). However, the use of mixed methods, or triangulation, use must not be viewed as a guarantee of either internal or external validity (Redfern and Norman 1994, in Begley 1996, p 125) and this is an argument that will be explored further in the Discussion chapter.

3.5 EXPLANATION OF THE RESEARCH PROCESS

A simple, descriptive overview of the research process was offered by Crotty (1998) providing a useful framework (outlined under the subheadings below) to address the theoretical process of the project and its design. It is important that the provision of such a breakdown does not oversimplify the research process but instead affords a deeper understanding of its various elements.

3.5.1 Epistemology

The epistemological position explains “how we know what we know” (Crotty 1998: p 3) or alternatively is the theory of knowledge that is embedded in the project’s theoretical perspectives and methodology. This project’s standpoint derives from a constructionist epistemology which regards how social phenomena develop in certain contexts. This project looked at the perceived challenges that health care staff identified when considering their experiences of dealing with and treating patients with learning disabilities. The staff’s perceptions of these challenges would have been constructed from social processes (Appleton 1997), including their own experiences, those of their colleagues and, for example, those described in professional or educational materials, of working with people with learning disabilities. Berger and Luckman (1966 read in Forss et al 1994) support this by stating that all knowledge stems from and is reinforced by social interactions. The project also looked at whether patient held communication tools could be used to improve awareness levels in staff caring for people with learning disabilities thus supporting the argument that learning (or improvements in awareness) is created by interactions (between the staff and the patient with learning disabilities) within certain contexts, including institutions (in this case the hospital).

3.5.2 Theoretical perspective

Providing an explanation of the project’s theoretical perspective is essential for the appropriateness of the methods used and the value of the findings to be judged. This is because the paradigm comprises a set of assumptions on which the formulation of the research questions is based. Williams and May (1996 cited in Walliman 2005 page 153) explain this by stating that:

> “all philosophical positions and their attendant methodologies, explicitly or implicitly hold a view about social reality … [which] will determine what can be regarded as legitimate knowledge”.

The philosophical underpinnings adopted for this project adopt an interpretevist stance, recognising the "unique personal theoretical stances upon which each person bases his/her actions" (Walliman 2005 page 167). Interpretevism is concerned with how reality is represented or perceived and acknowledges that different people interpret the world in individual, subjective ways. Meaning exists due to experience or engagement with reality (Crotty 1998). A particularly congruent aspect of the interpretevist paradigm for this project is its stance that the interpreter (or researcher) cannot be separated from the context of the investigation or its findings. The concept of the insider researcher is an inevitable element of a work-based project applying methods such as a nominal group exercise (this is further explored in section 3.6).

3.5.3 Methodology

The compatibility of the interpretevist approach can be further supported by looking at the project's methodology, which is the process underlying the choice of methods that provides the crucial link between these and the required or expected outcomes. The project's methodology was a case study of a service development. Before making changes to policy or practice, such as the implementation of hospital passports throughout an acute healthcare organisation, Macintyre et al (2001) state that it is first essential to establish an evidence base to inform this process. Yin (1984) advises that it is usual and preferable to do this prospectively by using or studying a particular case example. The benefits of the case study approach have been described as:

> *"Its ability to explore the real-life complexities of social contexts using a combination of quantitative and qualitative methods, with a strong emphasis on process as well as outcome measures"*
>
> (Inchley et al, 2000, p:200)

Whilst the project has been predominantly described as a case study, it also demonstrated characteristics of action research (a term generally accredited to the seminal theorist Lewin). Whilst this is fundamentally a problem solving methodology, the literature seems divided (or united in its

indecision!) about whether action research sits better under the guise of research or change management (for example Dick 2000, Carr and Kemmis 1986, Stringer 1996). The ultimate aim and outcome of action research is the achievement of change, which ties in with the required outcome of the work based Doctorate in Professional Studies in Health, involving the delivery of a programme achieving excellence in practice as well as the production of "original work that results in significant innovation and change within a profession and/or organisation" (Work Based Learning And Accreditation Unit 2006/7, page 15).

With reference to both action research and case study methodologies, it is not the methods that are specific to them, but their approach (Lilford et al 2003). Both are based on similar frameworks; action research comprises a cyclical process of synthesising theory with practice through planning, action, evaluation and then reflection (and repeating this if necessary), whereas case study research is based on the following stages:

- Definition of the research questions
- Selection of the case(s) and determination of the data gathering/analysis techniques
- Preparation for data collection
- Collection of data in the field
- Evaluation and analysis of the data
- Preparation of the report

Perhaps the major distinction between the two methodologies is the final reflexive component of action research which provides the opportunity to learn from experience by reflecting on what happened, and how / why it happened. For this reason, the framework of the action research methodology has been selected as a way of presenting the methods (see below) and findings (see chapter 4).

3.5.4 Methods

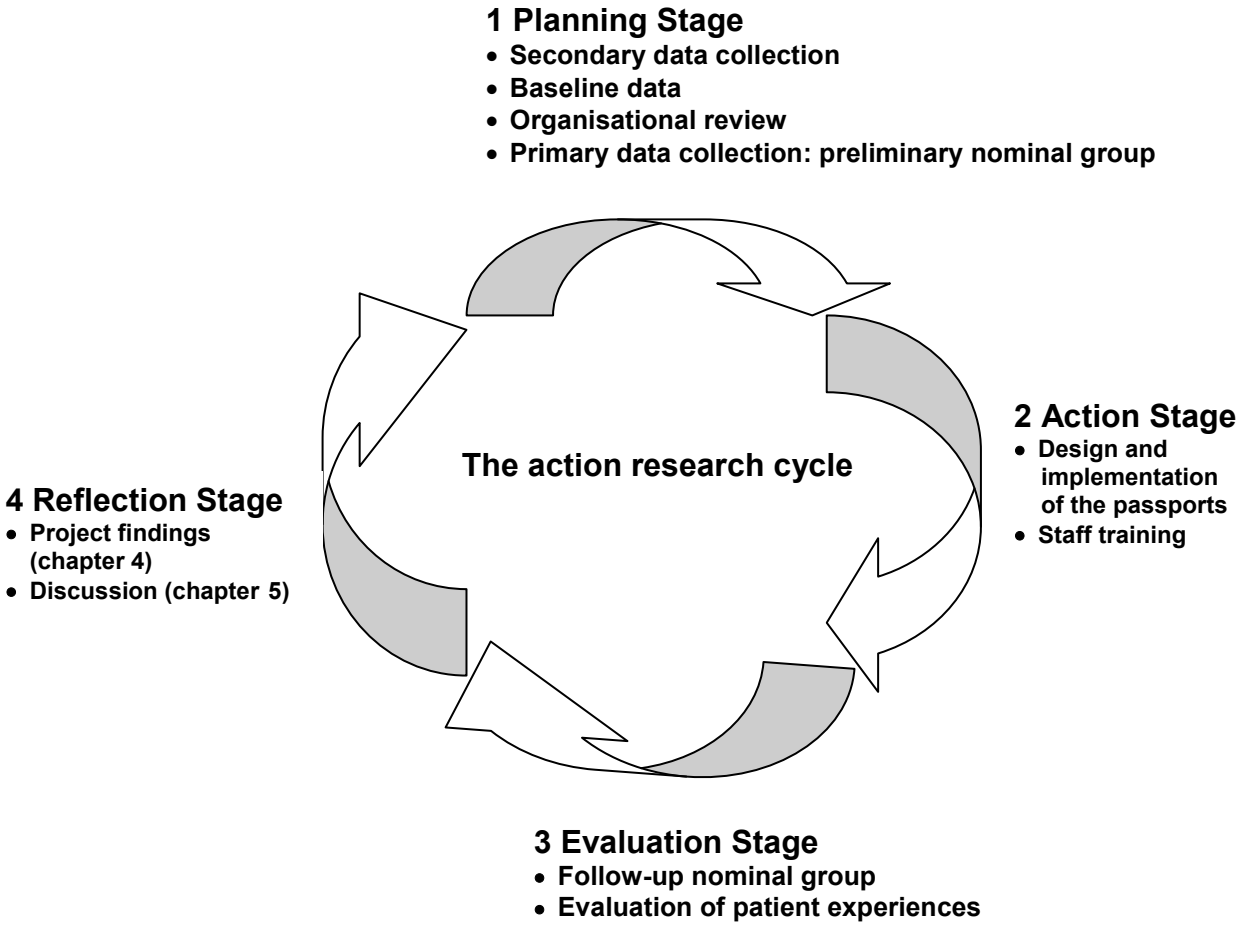
As has been noted above, the methods used in this project were conducted using an action research framework (see Figure A) and thus have been presented as so.

3.5.4.1 The planning stage

Secondary data collection

Conducting a literature review and gathering an evidence base for a Level 5 project is a considerable undertaking in itself. The term literature review is defined as “an interpretation and synthesis of published research” (Merriam, in Murray 2006, page 108) though of course secondary data collection also encompasses additional research, opinions and policies that may not at the time be published work. In addition to this, of course, is the unending amount of information available on the internet. A detailed outline of the secondary data collection processes is provided in Appendix M1.

Figure A: the action research cycle



Source: Adaptation for this project, based on Carr and Kemis (1986) and Dick (2000)

Baseline data about service users

Establishing a demographic and medical profile of service users with learning disabilities in order to identify the services that they used (or were likely to use) involved working with the hospital's Information Development Team. This department collates diverse information about patients (including their personal information, their reason for attending the hospital, investigations associated with their medical episode co-morbidities and so on) from information recorded on its two data systems. The first is the Patient Administration System which records, for example, details of attendances, reason for referrals, appointments and positions on waiting lists. PAS is operated predominantly by clerical and

administrative staff. The other is the Electronic Patient System that manages clinical information such as diagnoses and results of investigations. EPS data entry is done in one of two ways; either directly by clinical staff (frequently doctors) or by members of the Coding Department who electronically enter data based on coding forms completed by clinical teams at the end of a treatment episode.

Specific data requests were submitted by email to the Information Development Team and in response Excel spreadsheet reports were generated. (An example of one of the spreadsheets is available for information in the Appendix M2). The financial years 2005/6 and 2006-7 were selected in order to ensure that the data was as current as possible. The duration of two years was chosen to provide a picture spanning more than one year (which could have been atypical), whilst at the same time ensuring that the amount of data being analysed was manageable within the scope of the project. The requests initially sent to the Information Department involved data concerning the number of people with learning disabilities who used the hospital in each financial year, which services they used and the numbers of patients accessing each service. Information was also requested regarding the service users themselves (such as age and gender). This same information was then requested for all patients, to enable comparison of the profile of service users with learning disabilities with the generic demographic information. I analysed all spreadsheet data manually, and then double checked my own calculations (in some cases I also confirmed the findings using Excel functionalities, such as sort, sum and average).

Organisational Review

Perhaps the most elemental stage of the project was conducting an overarching organisational review as it established the current situation from where progress and recommendations for advancements could be made. The literature was searched to find suggested methods for conducting organisational reviews; no specific evidence was located but the search revealed a body of evidence regarding organisational performance, factors that influence it and systems for measuring it. From

a review and synthesis of related literature, Waggoner et al (1999) identified categories to be considered when looking at operational performance measurement comprising internal influences, process issues, transformational issues and external influences. The processes involved in the organisational review have been categorised according to these and full details of how they were conducted can be found in Appendix M3. The final category of external influences was not included here as it concerns issues such as legislation, which have already been addressed within Project Drivers (see section 2.2).

The organisational review comprised many different elements as it aimed to be as comprehensive as possible. However, it is recognised that limitations still existed in the methods due to the size of the organisation, which employs nearly 6,000 staff and the capacity of the project (which had a study hour guide of 1300 hours: Work Based Learning And Accreditation Unit, 2006 page 54).

Primary data collection: Preliminary Nominal Group

Selecting the Nominal Group Technique

Ascertaining consensus of staff opinion provided a useful baseline from which to assess the impact of hospital passports. Consensus methods enable opinions of a subject, about which there is limited understanding, to be consolidated (Moore 1987, in Carney et al 1996 page 1024) and are particularly effective for "making decisions when a number of people from different background and perspectives need to be involved in the problem solving process" (Van de Ven and Delbeq 1974, page 605). Consensus methods are, therefore, being increasingly used in healthcare as approaches to problem solving.

The decision to select a consensus method was also based on the need to avoid certain methods of data collection. The preliminary stages of project conceptualisation involved discussions with key figures in the hospital regarding the feasibility of conducting various methods of data collection. One nurse manager felt that staff were generally "audited out",

or in other words were experiencing subject / participation fatigue with reference to surveys and checklists. This could partially have been attributed to the recent, simultaneous NHS Litigation Authority assessment (NHSLA 2006) and National Inpatient Survey (Picker Institute 2007). Consequently selecting a data collection method that would be well received within the organisation was imperative, and it was hoped that using a consensus method would generate support, compliance and interest. This rationale also helped to identify which type of consensus method should be chosen; the Nominal Group Technique versus the Delphi technique[2]. Because the Delphi uses questionnaires, interspersed with feedback, this was eliminated on the basis that it involved an approach that staff might perceive as being "audited". Delphi also requires more time; Beretta (1996) estimates that each round of questionnaires takes about 45 days and as some studies have multiple rounds, such as the four rounds employed by Sumision in 1999.

The Nominal Group Technique explained

The nominal group technique (NGT) was developed in the late 1960s from psycho-social studies (Van den Ven and Delbeq 1974). The NGT has been used widely in healthcare settings for identifying priorities, ascertaining the appropriateness of interventions, and developing education and training (Jones and Hunter 1996). It involves a structured meeting that attempts

> "to provide an orderly procedure for obtaining qualitative information from target groups who are most closely associated with a problem area".
>
> (Fink et al 1984, page 980).

The nominal group (NG) comprises five major components; the question, the participants, the information (used to generate discussion and ideas), the method of structuring interaction (such as how many rounds are used and how scores are collated) and the method of synthesising individual

[2] A third type of consensus method was the consensus development conference (Jones and Hunter 1996, French et al 2001) which was not considered for this project.

judgement (Murphy et al, 1998). Further essential components include planning and observing group interaction (Jones and Hunter, 1996). Clear and user-friendly guidelines for administering NGTs were synthesised from Jones and Hunter (1996, pages 42-43) and Thomas (1983, page 335).

Participant sampling

Details of how the participants were sampled for the project's preliminary nominal group are provided in Appendix M3.1.

Conducting the Nominal Group

A session was booked on the induction programme and participant information (see Appendix M4a) was sent out by email to the attendees by the programme's administrative coordinator (this meant that I, as the researcher, did not need to know the names or personal details of the participants).

The NG was conducted in the hospital's training and development department which was the location of the Nurse Induction Programme. I started the session by introducing myself to the group and welcomed participants. Ground rules for the session were outlined and displayed throughout the session on a flip chart. These included the right to have opinions and the need for confidentiality of views expressed. A second participant information sheet (see appendix M4b) was re-circulated as a reminder for staff about the content of the session and information about NGT, its context and the reason for its selection. To gather a basic profile of participants, they were asked to complete an attendance form detailing their grade, speciality (such as Accident and Emergency or Paediatrics), length of service as a qualified nurse and age according to ten-year banding (i.e. 20-29, 30-39 etc). They were specifically asked not to provide their name or ward in order that comments could not be traced to individuals. The rationale for this was that it was hoped participants would feel more comfortable with contributing to the NG, by having their anonymity protected. Attendees of the induction programme were told

that their participation in the NG was voluntary and they were free to leave at any time before or during the group.

The research question was presented to the group: “What challenges do we currently face when working with people with learning disabilities?” Two stimuli were used to generated thoughts and ideas. The first was an excerpt from “Death by Indifference” (Mencap 2007: p 10 and 11) outlining the story of Martin who had severe learning disabilities. He was admitted to an acute hospital following a stroke and with pneumonia. In hospital he was unable to swallow and consequently was put on a drip. However due to severe failings in the care provided, he remained on the drip for 26 days and died due to inadequate nutrition. The second stimulus was a short video produced by people with learning disabilities for people with learning disabilities, entitled “Let’s be patient” (Taking Part 2004). It shows the patient’s journey from receiving a letter from the hospital, to attending an appointment at hospital. It was produced as an aid to help prepare patients with learning disabilities for forthcoming admissions but was also intended by its producers to be used as a training tool for staff to present a patient’s experience.

Participants were invited to spend five minutes silently writing down their ideas and views in response to the stimuli. Each participant, in turn, was asked to contribute an idea, which was recorded by the facilitator on a flip chart. This process was repeated by going around the room until all ideas were on the board; all pages of the flip chart were constantly displayed so all ideas were in view. Participants could pass on rounds and re-enter in a later round if they wanted. One of the benefits of the NGT according to Jones and Hunter, (1996) is that participants can hear opinions of others, which in turn can generate fresh ideas. The facilitator attempted to note any interesting group dynamics or behaviour concurring with the consideration of ideas. Ideas that were very similar were grouped together and a brief group discussion was held to clarify and evaluate each idea to avoid any ambiguity.

The first round of ratings then took place; participants were given three index cards on which to write the three ideas that they identified as being the most important. They were then asked to allocate a score of 3, 2 and 1 (the score of 3 being allocated to the most important and then descending score to 1 for the least important of the chose ideas). The index cards were collected by the facilitator and the scores were recorded by the facilitator on the flip chart next to the idea. The total score for each idea was calculated and written on the flip chart. Participants were asked if they wanted to add any further ideas and / or re-rate them. These ideas with the lowest scores were disregarded and the remaining items constituted the reaching of agreement (consensus) about the most important challenges that staff felt they faced when working with patients with learning disabilities. These ideas were then ranked in order, starting with the idea with the highest score.

Participants were also provided with forms for free comments, such as recording their feelings about ideas that had been removed. These were collected randomly by one of the participants who gave a pile of forms back to the facilitator; this promoted the issue of anonymity of as individual participants could not be linked to their feedback forms. The production of two data sets from one method (i.e. the ratings and the free comments) is described as within-method triangulation (Begley, 1996), the merits of which will be discussed in the Discussion chapter.

As participant names were not collected, the facilitator's contact details were displayed at the end of the NG on a flip chart for participants to take note in the event that they might later have questions about the group or its results.

The rationale for using the Nominal Group Technique

Assessing the suitability of the NGT as a data collection method involved multiple considerations. The findings of studies about the reliability, validity and impact of consensus methods are mixed (Horn and Williamson cited in Fink et al 1984, p979). However, potential doubts about the suitability of the NGT can be addressed by justifying the

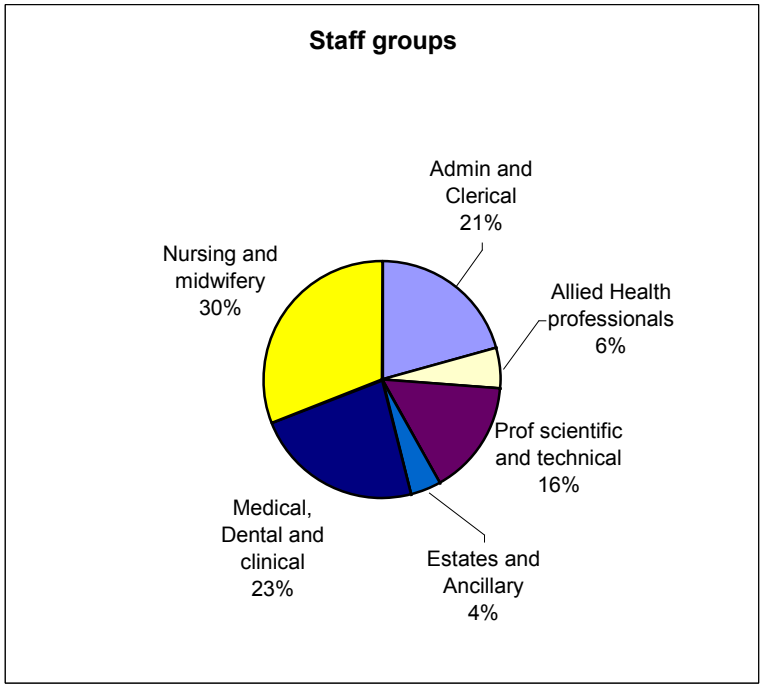
reasons for selecting it (Jones and Hunter 1996), careful disseminating the findings (Fink et al, 1984) and following the guidelines for conducting the groups (Thomas 1983). A significant benefit of using the NGT is that it is inexpensive; project funds were not available and it was necessary to absorb any costs within the roles and scopes of the members of the Project Overview Team.

The participants of the NG were all qualified nurses whereas staff from many different professional backgrounds and departments are involved in the care of patients with learning disabilities, including administrative staff who make appointments, drivers who transport patients, therapists and so on. It was felt, however, that this was an appropriate sample within the scope of the project and as nurses would be the main staff group involved in the use of the passports at ward level and as it is known that nurses form the largest group of staff in the NHS (NHS Careers 2008). The Work Force Planning Department reported that, at the time of writing, the number of staff employed by the organisation was 5871 and a breakdown of the staff groups is indicated in Figure B with approximately 30% of those being nurses.

The Project Overview Team agreed that the intervention could be focused on nurses and then rolled out after any necessary alterations had been made. The author was unable to identify any guidelines regarding the sampling of participants; in fact an evaluation of the evidence concluded that there is insufficient research to be able to support the development of any such guidelines (Murphy et al, 1998).

The literature advises that the leader or facilitator of the NGT need not be an expert in field but as they are also a participant, they therefore must have subject matter expertise (Fink et al, 1984). The leader also needs to have a level of credibility with participants and experience / competence in coordinating group exercises. Due to a strong professional background in team management, training and with experience in facilitating groups, I considered that I was qualified to be effectively facilitate the NG.

Figure B Composition of staff groups for 2006/7



Source: St George's Hospital Annual Report 206/07

3.5.4.2 The action stage

Design and implementation of the passports

The action stage of the project involved the implementation of the Hospital Passports for use by patients with learning disabilities with scheduled elective (planned) admissions to the hospital. The passports were designed by the Project Overview Team in partnership with service users with learning disabilities. The passport evolved through four draft stages and service users (see Project Overview Team in Chapter 2) were involved with each stage by having the opportunity to comment on the wording and layout. A final version was achieved when no further amendments were suggested by any of the service users. The timeline of the passport development was concurrent with the early stages of the project planning by the Project Overview Team (see Appendix M5).

The passports adopted a traffic light communication system and were based upon similar tools developed by other services; in particular one

developed by a learning disability team in Gloucestershire (Corbett 2007). The traffic light system is very visual; red covers essential need to know information (such as name, address, next of kin details), amber describes information that would be very useful for caring for the patient (such as diet preferences) and green provides information that would be useful for the nurses to read though not necessarily urgent on admission (such as likes and dislikes). The passports were printed in full colour and with the front cover laminated to make them as striking and identifiable as possible (an example of the passport can be found in appendix M6).

The Learning Disability Nurse Manager and the two Learning Disability Nurses identified clients in the community who had forthcoming admissions to hospital who might also benefit from having a completed Hospital Passport. Potential clients were identified from the nurses' caseloads and from liaising with care homes and care providers within the local area. Passports were completed with/by the person with learning disabilities (and/or a person nominated by them), with the consent of the patient or next of kin (if appropriate) and with support from the Practitioner if needed. It is very important to convey that this element of the project was conducted by other members of the Project Overview Team; I was involved by proxy in the form of discussing it during meetings. The decision not to be directly involved in this aspect of the project was in recognition of the specialist expertise, and familiarity with individual service users and their families of other members of Project Overview Team (see Ethical Considerations).

Staff training

It was recognised that successful introduction of the passports in the organisation would depend on preparation and education of staff about recognising and using the documents. Once a patient had a completed passport, the learning disability nurse telephoned either the Deputy Director of Nursing or me to advise of their imminent, elective admission. Training was then provided by me the Deputy Director of Nursing in the form of pre-arranged but informal meetings with ward sisters and senior sisters in the clinical area to which the patient would be admitted. The

meetings with the nursing staff involved showing them a passport, explaining how to use them and agreeing how the information would be disseminated throughout their nursing team to ensure that as many nursing staff as possible would be prepared for the use of the passports. In the event it was not possible to identify or predict on which ward the patient's bed would be, meetings were held with members of the nursing staff on all possible wards (for example on four wards that provided post orthopaedic surgical care for a patient having an arthroscopy). Posters/flyers advertising the passports and offering support (in the form the contact details of the Learning Disability Nurse Manager and team) were distributed to all wards via the nurse information dissemination structure.

Twenty patients using passports were admitted to the hospital during a six month period (January to June 2008). Specific guidelines for using the passport were not issued to the patients, though suggestions were discussed at the time of completion of the passports such as showing their passport to the nursing staff at the point of arrival on the ward. It was felt that it was important that the use of the passports was patient-led, or in other words the passports were used in a way in which the patients felt supported communication and with which they were comfortable.

3.5.4.3 The evaluation stage

Follow-up nominal group

To evaluate whether the elements of the Action Stage were effective in increasing staff awareness of the needs of people with learning disabilities, it was necessary to conduct a follow-up NG. It is important to note that comparisons drawn between the preliminary and follow-up NGs do not constitute a before and after study. The NHS Knowledge Service advises that a:

> *"Before and after study is a study in which characteristics of a population or a group of individuals are compared before versus*

after a particular event or intervention, for example the introduction of a new healthcare service, to gauge what the effects of the event or intervention have been".

(NHSKS, 2008: webpage)

The definition appears to apply to this study in which the characteristics (awareness levels) of a group of individuals (nursing staff) are compared before (at the beginning of the project) versus after (after 22 weeks) a particular intervention (implementation of the passports). However, there seems to be general agreement (such as Support, 2008 and Ray-Coquard et al, 2002) that in order for a before and after study to be accurate and of use, there is an additional requirement that the study should be controlled. It was not possible to repeat the NG with the same participants (see Appendix M6.1) because it was not possible to predict that they would be exposed to, and have the opportunity to care for, patients with learning disabilities using hospital passports. In addition, it was not possible to match the characteristics of participants of the follow-up NG with those of the preliminary NG; a new intake of Induction Programme attendees, who would predominantly be new to the organisation, would not have been exposed to the Hospital Passports. Furthermore, it would not have been possible for the second NG to have generated identical items for statistical analysis. Therefore, this element of the study can best be described as a longitudinal comparison drawing on thematic similarities and differences between the awareness levels of two groups of nurses over a five and a half month (22 week) period.

Participant sampling

Details of the sampling methodology employed for the follow-up nominal group are provided in Appendix M6.1.

Conducting the group

The follow-up NG was administered using the same guidelines as for the first NG. I opened the session by introducing myself to the group and welcomed participants. Ground rules for the session were outlined and displayed throughout the session on a flip chart. Participant information

was circulated outlining the content of the session and including, as a reminder, information about NGT, its context and the reason for its selection. Participants were again asked to record some basic personal information on an attendance form such as their grade and speciality. This was used to compare the participant profile with that of the first NG. The anonymity of participants could not however be assured as it had in the first group because the facilitator knew some of them from previous patient information collaborations. Attendees of the Sisters' Meeting were told that their participation in the NG was voluntary and they were able to leave at any time before or during the group.

In this NG, two research questions were presented to the group:
Question 1: "Have hospital passports made a difference to how you work with patients with learning disabilities? If so, how?"
Question 2: "What challenges do we still face when working with patients with learning disabilities?

Two stimuli were used. Firstly, the excerpt from "Death by Indifference" (Mencap, 2007) used in NG1 and a completed, anonymised example of the hospital passport. The facilitator showed it to the group, described its contents and passed it around for the participants to take a closer look.

Participants asked to silently write down their ideas and views in response to both question for seven minutes (a slightly longer duration than NG1 was allowed as the participants were considering two questions). The questions were then dealt with separately; the facilitator recorded the ideas in response to Question 1 on a flip chart by going around each participant in turn and continuing until there were no further ideas. Any overlapping suggestions were, again, combined. A different rating system was used for NG2 due to the time constraints relating to participants considering two questions. The participants were given scores of 3,2 and 1 (with 3 as the most important) and one and asked to write their own scores next to the ideas on the flip chart sheets that were displayed around the room. The scores were then added up and the total scores were written next to each idea. The items with the lowest scores

were disregarded and the remaining items constituted the reaching of agreement (consensus). Participants were asked if they wanted to add any further ideas and / or re-rank them.

As in NG1, participants were also provided with forms for free comments, such as recording their feelings about ideas that had been removed. These were collected randomly by one of the participants who gave a pile of forms back to the facilitator; this meant that feedback could not be linked to individual participants. Once again, this produced two data sets from one method and further strengthened the application of within-method triangulation; two types of data were generated from one method applied on two separate occasions (Begley, 1996). The facilitator's contact details were provided in case participants wanted to later enquire about the group or its findings.

Evaluation of patient experiences

Patients who had used passports during their admission, and thus who had been purposively sampled, were contacted post discharge by the learning disability nurses. The patients and their carers were asked if they would like to take part in an evaluation of the passports and meetings were held with those who consented. The meetings were held about a week after leaving hospital, allowing the patient to settle at home but not leaving too long a period in which important data could have been lost/forgotten.

The evaluation involved a semi-structured interview with the patient and carer; this method of data collection was selected due to its flexibility as it meant that the interviewer could reword questions if needed and to check that they have been understood. The nature of learning disabilities means that the person has impaired intelligence (DOH 2001) and therefore is likely to have difficulties in following instructions (Godsell and Scarborough 2006) which would be essential for participating in research. This could be further complicated by the possibility that the service user may have additional difficulties of expressive and receptive communication difficulties (Hogg 2001) or challenging behaviour (Brown

2005). Although Whiting (2008) advises the use of structured interviews with closed questions for people with communication difficulties, the Project Overview Team felt it would be difficult to elicit personal responses in this way. The semi-structured interview, on the other hand, allows the interviewer to deviate on themes and support the service user with the process.

The interviews about the patient's experience were conducted by the learning disability nurses. The form used for the interview (Appendix M8) listed eight questions agreed by the Project Overview Team. The form was used to record the patients' responses, which were noted as fully as possible though not necessarily verbatim. Before commencing, the nurses checked with the patient, and their carer if appropriate, that they still wanted to proceed. A key feature of semi-structured interviews has been identified as taking place in a location outside of everyday events (DiCiccio-Bloom and Crabtree, 2006). However, Clark (2006 cited in Whiting, 2008: p 36) suggests that the respondent is asked where they would like the interview conducted. All of the interviews were conducted in the patient's home or usual residence (such as a residential home) as requested by the patient/carer.

The benefits of using patient experiences to inform practice and education as well as improve healthcare quality are well documented (such as in Warne and McAndrew 2005). The data generated by the patient evaluation enhanced the project findings overall by providing the experiential, user-perspective often needed in health service research. As with the completion of the hospital passports, I decided not to take part in the interviews mainly in recognition of personal limitation of specialist skills and recognition of possession of these skills in others. The learning disability nurses knew all of their patients whom they interviewed; this was felt to be important as Whiting (2008) advises that building rapport is an essential component of conducting interviews. The consideration of ethical issues (see section below) further strengthened the reasoning for the interviews to be led by the learning disability. The learning disability nurses sought advice and approval from their own

organisation's (the PCT) research governance department regarding conducting interviews with service users. It was considered that asking questions of service users about a new initiative to improve access to services was part of their professional remit. The nurses were advised, in particular, to reassure patients that declining to take part or providing negative answers would not affect their care or treatment in any way.

3.5.4.4 The reflection stage

Although the reflection stage is labelled as the final stage in action research, it is essential to recognise that reflexivity is embedded from the outset. The process of reflection within the context of healthcare practice and research is an essential component of service improvement and practice development. Healthcare professionals use reflective practice to consider an event (or events); it provides an approach to working out why and how it happened, considering the positive and negative influences and outcomes involved. Importantly it also shapes what can happen next time the event occurs as the practitioner may be able to influence one or more of the associated variables.

One of the distinguishing factors of a Doctoral project is the level of reflexivity and criticality, which takes the process of reflection considerably deeper. Willig (2001) outlines two types of reflexivity: personal and epistemological, both of which are essential to consider. Personal reflexivity requires the researcher to consider his or her own values and identity and how these can contribute to the construction of meaning or meanings (Nightingale and Cromby, 1999). An example of this is how the researcher's judgement can affect the phenomenon under investigation as well as the findings of the research. Reflexivity places the researcher at the centre of analysis of research for the whole process; in other words it is not just the findings that are inextricably related to the researcher but the processes associated with each component of the research project. Within action research, the final stage of the cyclical process, in every cycle, is reflection. However, it is essential to convey how, for example, issues of rigor and ethics, and the role that the researcher plays in these, have been considered throughout the project

from the outset, rather than merely at the end as a retrospective process (though it is also important not to underestimate the value of retrospective analysis). Additionally, in action research there is opportunity for further embedment of reflection to continue beyond the first cycle of action as the research process starts again.

Another element of personal reflexivity involves how the research affects the researcher. To understand this requires developed self awareness of not only 'what have I done?' but also 'what will I do or do differently?' as a result. Hughes (2006: p3) agrees, describing both a "readiness for action" and "commitment to action" as outcomes of reflexivity. These will be explored further in the Conclusion / Recommendations chapter.

Epistemological reflexivity requires us to question, in an ongoing manner, the efficacy of the research question(s) and design as well as the analysis of the research findings. In order to do this, it is useful to consider some questions, such as:

> *"How could the research question have been conducted differently? To what extent would this have given rise to a different understanding of the phenomenon under question?"*
>
> (Willig 2001: p10)

The aim of epistemological reflexivity is the pursuit of the highest standards of research, and it must be recognised that it does not encourage the covering up of the research shortcomings. A confessional approach was first proposed by Burgess (1984, in Hughes 2001: p5) encouraging as much honesty as possible when conducting and writing about research. With this in mind, the limitations of this project are hopefully articulated with clarity in the Discussion chapter.

It seems to be well recognised that that keeping a research diary is a way of enhancing reflexivity in research, particularly in action research contexts (for example, Blaxter et al, 2001 and Nadin and Cassell, 2006). A decision was made in the conceptual stages of the project to keep a

research diary, partly to track the many strands of the project and also as a reflective tool. Using the diary entries to integrate and interrogate both personal and epistemological processes required considerable application but it is hoped that this helped to ensure high levels of rigor and ethical soundness within the project as well as contribute to my own personal/professional development.

3.6 Ethical considerations

It has been said that it is too simplistic to state that the beneficiaries of research will be the participants or the general area of health science (Polgar and Thomas, 2000). The ethical considerations go far beyond addressing who stands to benefit; issues of consent, protection of participants, gaining approval and data protection all need to be carefully considered. Interestingly, Denscombe (2003) warns of the dangers of overlooking ethical issues when a project is identified as action research. Therefore thorough attempts have been made to address, in Appendices M9 (Ethical Considerations) and M10 (Letter from LREC), all associated ethical issues in order to ensure the integrity of the project, encompassing:

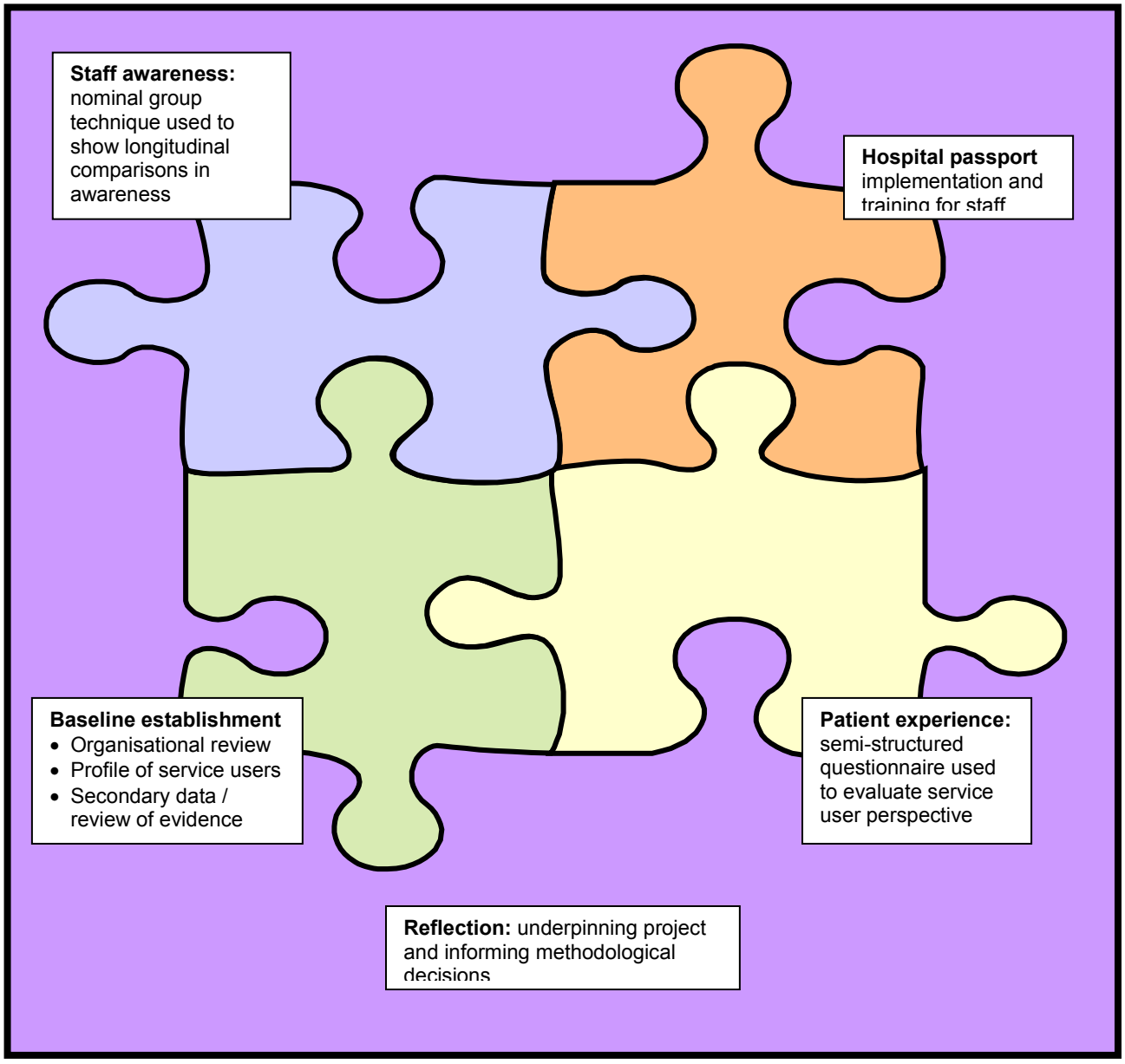
- Professional codes of conduct
- Ethical approval
- Data handling
- Issues of the 'Insider Researcher'
- Ethical Issues associated with the NGs
- Involving Service Users with Learning Disabilities.

3.7 CHAPTER SUMMARY

This chapter has aimed to outline the multifaceted aspects of this project and how it has been underpinned by its epistemological, theoretical and methodological constructs. By way of summarising the project design and to provide clarity regarding all the steps involved, the following diagram (Figure B2) is offered. Although primitive in appearance, the jigsaw aims to show how all the inter-locking components of the project "fit together". Both the evaluation of patient experiences and the measurement of staff awareness were directly linked to the implementation of the hospital

passports. The fourth piece of the jigsaw shows how the context of the project (the baseline data) completes the picture. Importantly, the whole jigsaw is set against a background of reflection and criticality.

Figure B2: The interlinking project design components



CHAPTER 4

PROJECT FINDINGS

This chapter aims to outline the project findings by presenting the results of each method of inquiry; for clarity, a summary of each section has been provided in a shaded box. The following chapter (Chapter 5: Discussion) is concerned with the interrogation and interpretation of the findings, particularly within the context of the existing knowledge base.

4.1 BASELINE DATA ABOUT SERVICE USERS

Preliminary information provided by the Information Development Team (IDT) showed that 425 people with learning disabilities were patients of the hospital in the 2005/6 and 2006/7 financial years (240 patients in 05/06 and 185 in 06/07). However, two flaws were immediately identified in this preliminary data. Firstly, it was noted that the figures indicated the number of patients coded as having a "Developmental disorder of scholastic skills, unspecified" (code F81.9). The entire database of diagnoses and their codes was then requested; a thorough examination of the 12,436 codes revealed that that a further 108 codes related to, or could be interpreted as being related to, learning disabilities. These included, for example, codes related to mental retardation, Down's syndrome and problems related to life-management difficulty (Appendix R1.1 details all the codes extracted from the database). This highlighted a major limitation, and potentially huge under-indication in the data, as it was reliant on the person recording the episode of care on the hospital data system (s) having a good understanding of learning disabilities, the different diagnoses that it covers and the differences between them.

Secondly, inspection of the preliminary data generated by the IDT showed that only patients with a primary diagnosis with a "Developmental disorder of scholastic skills, unspecified" had been identified. In fact, there is scope to electronically record a primary diagnosis and a further five diagnoses for each patient. The inclusion of learning disabilities as diagnosis would be dependent on the nature of the episode, and would rarely be the reason for admission. For example, an emergency admission of a learning disabled patient due to a road traffic accident (RTA) resulting in a fractured pelvis and

fractured femur could be recorded as the primary (RTA), first (pelvis) and second (femur) diagnoses; learning disability may or may not be recorded subsequently in one of the three remaining fields. Therefore the face validity of the generated data was once again challenged and the IDT were asked to report details of patients with any of the 109 possible learning disability codes recorded as any of their diagnoses.

The data shows that 584 people with learning disabilities were patients of the hospital in the 2005/06 and 2006/07 years (304 patients in 2005/06 and 280 patients in 2006/07). The overall figure for the two years of 584 patients is a 19% increase on the original data sent by the IDT and demonstrates the potential for discrepancies. The total number of patients using the hospital was 93,882 patients in 2005/6 and 103,877 patients in 2006/7, totalling 197,759 in the two year period. Therefore the percentage of learning disabled patients using hospital services across the two year period was 0.3% of all patients (which cannot be usefully graphically represented). On first impressions, this appears to be a very small number of patients but perhaps if considered as 3 patients in every 1000, the scale is more apparent.

It is also important to acknowledge that these figures are certainly an underestimation of the actual number of service users with learning disabilities, as they relate to patient admissions and day cases only. At the outset of the project, data was required to provide a picture of service users rather but it transpired that data regarding outpatient episodes requires much more specificity as it is apparently more complex to extract. Consequently the IDT attach a (fairly substantial) financial cost to such requests, and as funding was not available for this (there were no dedicated project funds), the data shown reflects inpatient / day cases only and does not pertain to outpatients. Although this is a recognised limitation, it is consistently applied to data relating to patients with learning disabilities and data relating to the total population of patients using the hospital (referred to hereafter as the total population of patients) and therefore the data is relative within its comparisons.

The original intention was to collate data regarding the services used most frequently by people with learning disabilities, though this proved to be impossible. Although the coding system recorded diagnoses, consultant and ward / unit, this did not precisely constitute information about a clinical service. For example if an older patient with learning disabilities suffered a stroke, they could either be admitted to an elderly care ward where their care would be coordinated by a geriatrician, a medical ward where they would be looked after by the medics or geriatricians, the stroke unit where they would be seen by the neurologists or geriatricians. The data for any of these scenarios could be represented in vastly differing manners, despite the basic data about the patient remaining the same. Therefore, it was decided for the purpose of establishing a profile of service users with learning disabilities and comparing that to the profile of the total population of patients, primary diagnosis (also known as reason for admission) would be used. This information is presented in Table 2, below. It can be noted that six of the primary diagnoses of the total population of patients were not found in the primary diagnosis information for any of the 584 patients with learning disabilities. The most common primary diagnoses of patients with learning disabilities related to three categories of dental medicine, neurology and cardiovascular medicine. The issue of diagnostic variation presents in two ways; both are explored in the following chapter. Firstly, a variation in diagnosis could exist depending on the skills of the doctor treating the patient. One doctor may record the fact that a patient has a learning disability, whereas another may not. The second type of diagnostic variation relates to the differences between the diagnoses of people with learning disabilities and the total population of patients.

A basic demographic profile of service with learning disabilities was also extracted for comparison with the profile of the total population of patients (see Table 3 below). The average age for patients with learning disabilities was lower (exactly half for 2005/06) than for the total population. The ratio of male to female patients for people with learning disabilities (27:23) was converse to the total population of patients (24:26).

Table 2: Ten most common reasons for admission (primary diagnoses) (combined for 2005/06 and 2006/07 years)

	Total population of patients	**Patients with learning disabilities**
1	Chronic renal failure (122)[3]	Dental caries (63)
2	Single spontaneous delivery (n/a)[4]	Encephalitis, myelitis and encephalomyelitis (>500)[5]
3	Chronic ischaemic heart disease (62)	Epilepsy (105)
4	Pain in throat and chest (154)	Complications with cardiac and vascular prosthetic devices, implant or grafts (182)
5	Malignant neoplasm of the breast (n/a)	Gingivitis and periodontal disease (135)
6	False labour (n/a)	Other diseases of hard tissues of teeth (>500)
7	Abdominal pain (n/a)	Iron deficiency anaemia (139)
8	Multiple myeloma and malignant plasma cell neoplasms (n/a)	Sickle cell disorders (43)
9	Atrial fibrillation and flutter (67)	Other lipid storage disorders (>500)
10	Medical abortion (n/a)	Malignant neoplasm of pancreas (74)

[3] Number in brackets indicates position on the database of descending prevalence of diagnoses for the other group of service users. For example, chronic renal failure is 122nd on the list of primary diagnoses for people with learning disabilities.

[4] Where N/A shown, the diagnosis was not found on the list of primary diagnoses for the other group.

[5] Where >500 is shown, the diagnosis was not within the first 500 most common primary diagnoses.

Table 3: basic demographic information about patients

	Total population of patients	**Patients with learning disabilities**
Average age		
2005/06	54.5	27.2
2006/07	55.4	33.4
Sex (male: female)		
2005/06 + 2006 / 07	24:26	27:23

Summary of Baseline Data

- 584 patients with learning disabilities used the hospital in 2005/06 and 2006/07; this is 0.3% of the total population of service users.
- These figures could be under-representative because:
    - outpatient data was not available
    - their accuracy is dependent on the data inputted.
- The most common diagnosis for patients with learning disabilities was dental caries. The primary diagnoses of patients with learning disabilities differed significantly from those of the total population.
- The average age (in 2005/06) of learning disabled patients was exactly half that of the total population of patients.
- The male: female ratio for learning disabled patients was 27:23 (1.2:1).

4.2 ORGANISATIONAL REVIEW

This section has been presented using Waggoner et al's (1999) categories of organisational performance measurement, as outlined in the Methodology chapter.

i) Internal influences

The organisation's policy manual is available electronically on the intranet site and in hard copy format located in a key office in each wing of the hospital. Searching the hospital's electronic policy manual took in the region of eleven hours. The 244 policies are divided across seven sections, and subsequent subsections. The executive summary of each

were searched for references to disability and vulnerable people. The methodical search of the electronic policy manual was followed up with a search using the intranet search facility, designed to locate search terms within any document on the electronic system. Despite prior consultation with the Computer Services department, it was discovered that the search facility was very unspecific. The facility did not accept word truncation (such as disab for disability, disabilities, disabled) or wild cards (such as * to replace the end of a word and expand possible matches). It also did not have the capacity to search for linked word or phrases (such as learning disability). These limitations consequently meant that there was a considerable amount of manual trawling through the electronic hits / matches.

The term “disability” showed 705 hits which were displayed in descending compatibility with the search term. The first 50 were scrutinised by reading the four line synopsis displayed on the screen. The rationale for looking at the first 50 of 705 hits was based upon the results being presented by relevance percentage. In other words, the first hit shown by the search facility was had the most relevant content (98%) to the search term of “disability” and they were presented in descending order of relevance thereafter. Only three of the hits related to policies and all of these had been previously identified in the search of the policy manual. It did however reveal two new documents worthy of scrutiny; the Disability Equality Scheme and the Single Equality Scheme. The relevance percentage dropped considerably after the first three hits as all other remaining hits were job descriptions where the statutory requirement information included adherence to the Disability Discrimination Act. By the time I had scrutinised the fiftieth hit the percentage relevance was down to 3% and therefore the decision was made not to look at the remaining 655 documents.

The term “vulnerable” revealed 603 hits, two of which related to the Safeguarding Adults Policy (discussed below) and the rest concerned job descriptions. “Intellectual” (searched in relation to intellectual disability as an alternative description of learning disability) displayed 17

hits, all of which were about intellectual property (for example in relation to information governance) or intellectual development (regarding play in a paediatric setting).

In sum, of the 244 policies in the hospital manual, nine (3.6%) included specific references to disability or vulnerable people (four policies within the Clinical Volume, three within the Organisational Volume and two within the Human Resources Volume). Detailed findings of the policy search are presented Appendix R1. An overarching policy exists (the Production, Approval and Implementation of Corporate Policies or the policy for policies as it is known) stipulating that an Equality Impact Assessment should be conducted for, and included in, all policies. This approach aims to encourage the thorough assessment and consultation of the effects that a policy is likely to have on all patients including those from minority ethnic backgrounds, those with disabilities and so on. Despite this, only two policies (0.8% of policies) specifically mention learning disabilities. Firstly, the Complaints and Concerns Policy and Procedures states that written complaint responses should be produced in an accessible format if the complainant advises of a learning disability. Secondly, the Patient Information Policy outlines the responsibility of NHS staff to produce and issue patient information in an accessible format and suggests ways in which information can be enhanced for people with learning disabilities. However, whilst many of the policies pertain to effective communication with patients and provision of information, they do not specifically acknowledge particular support needs of patients, including those with a learning disability. Additionally, it was noted that the patient information sheets included in the appendices of many policies were not presented in alternative formats (such as large print, supported by images or in other languages).

Interestingly, two examples of the potential for misunderstanding within the organisation were noted during the policy search. Firstly, the Safeguarding Adults policy was expected to be one of the most relevant to the care of people with learning disabilities, but it only sets out

guidance for action in the event of suspected abuse and does not deal with proactive measures to support and advocate for vulnerable people. It also does not stipulate who would be considered or classified as a vulnerable adult. Secondly, it was anticipated that the Access Policy would relate to improving access to the site or services for disabled people, but it actually conveys the organisation's standards for waiting list management and monitoring.

Other strategic documents that were identified included "Our Values", which is a summary of the most important things guiding the work of the organisation. Whilst the document does not mention disability specifically, one of its objectives is "to ensure that services are accessible, responsive, and meet the needs of our patient populations" (St George's Healthcare NHS Trust, 2008: webpage). Details of how this will be achieved or who the patient populations comprise are not outlined. Another identified document, the Single Equality Strategy 2008, sets out how the organisation proposes that it will respond to legislative requirements regarding race, sex and disability. With reference to disability, it cross references the Disability Equality Scheme (DES) which specifies how the organisation will ensure the DDA (OPSI 2005) is implemented. The DES includes an action plan sets out aims to improve access for disabled people including adjustments to the site / equipment, patient involvement strategies, staff training and interagency working. Learning disabilities is not singled out as requiring a specialist approach. No references to the identification or response to the needs of patients with disabilities were located in the Clinical Services Strategy 2005-9, Annual Reports 2005/06 and 2006/07 or the Training and Education Strategy 2007.

ii) Transformational issues

Roles and responsibilities were described by Waggoner et al (1999) as the elements of an organisation that drive transformation. The Chief Executive was asked how he perceived his role as being responsible for the care of people with learning disabilities. He responded that he was ultimately accountable for the implementation of all legislation regarding

accessibility and that he did this via the committee structure which ensured that implementation of objectives and lines of accountability.

Identifying committees and groups that could be responsible for promoting the care, and access to care, of patients with learning disabilities involved a methodical review of an organogram (a diagram depicting management and accountability structure). It was known that this was a recent document as it had been submitted as part of a recent NHSLA assessment that took place in December 2007. Five main boards feed into the Trust Board, namely Clinical Management, Remuneration, Audit, and Finance and a further fifty six committees feed into these. The Governance Committee was the umbrella under which patient management policies and strategy sat and was accountable to the Clinical Management Committee. A meeting was held with its chair, the Head of Governance, to enquire how she perceived her role as being related to the care of people with learning disabilities. She responded by stating that she oversaw processes that ensured equity of access for all patients, relying on the work of sub-committees (see Appendix R2 for a diagrammatic representation) and their assurances provided in the form of reports)
The leads of sub-committees proposed by the Head of Governance as being concerned with the care of disabled people (indicated in Appendix R2 as shaded areas) were contacted by email to request their group's terms of reference. These were reviewed for the inclusion of terms relating to disability and more specifically learning disability. Of the seven committees nominated, six specified their responsibilities regarding disability in their terms of reference and two mentioned learning disabilities; extracts from these documents can be found in Appendix R3.

iii) Process issues

This element of the organisational review involved investigating the mechanisms for identifying patients with learning disabilities, such as data collection and recording methods. A meeting was held with a

member of the Coding Team regarding the functionalities of the Patient Administration System (PAS). This revealed that there is no electronic facility to identify or flag-up any special requirements, such as the need to receive letters in an accessible or alternative or format. In addition, PAS does not have a free text field (i.e. in which a note could be made that a patient has a learning disability) on its home page; this is only available in the screen associated with each episode such as for an appointment. This would mean it is reliant on the data-imputer to cross check previous appointments/admissions each time a new one is entered; something that would not feasibly happen in reality. Investigations about the data system revealed that a new system (iClip) will be implemented across the organisation from early 2009. This will have the scope to have an alert regarding the patient's needs, though will be limited in space and therefore will be unable to accommodate, for example, an allergy and a disability.

In order to find out how staff, in general across the organisation, felt they identified and/or met the needs of patients with learning disabilities, a message was posted on the electronic hospital bulletin board. Despite this forum usually generating considerable responses (e.g. a request for a printer cartridge on the same day received fourteen replies), no responses were received.

The manager of the Central Booking Service (the "call centre" that plans all outpatient appointments) and the lead discharge nurse were contacted by telephone to enquire whether, within their teams, there were any protocols regarding disabilities, and more specifically for learning disabilities. There were no special arrangements in place when making appointments for patients. In fact if a patient failed to confirm that they required their appointment or did not attend an appointment, their name would be removed from the waiting list and a letter sent to the patient's GP. The manager was confident that processes were in place for the GPs of disabled patients to then contact the Central Booking Service. The lead discharge nurse explained that the relevant agencies would be contacted regarding the discharge of a

patient with complex support needs. The information about the agencies involved in the care of the patient would be gleaned from the patients nursing, medical or multi-disciplinary notes, from the patient, or from the GP. Shortcomings in both of these systems are discussed in the following chapter.

Summary of Organisational Review

- Of 244 organisational policies, 9 (3.6%) policies refer to disabilities or vulnerable people and 2 (0.8%) mention learning disabilities.
- There is potential for confusion in the terms used in some policies (e.g. the access policy relates to waiting lists not to access for disabled people).
- Of the seven strategic documents searched, only the Disability Equality Scheme refers to the organisation's responsibility to disabled people. It does not specify learning disabilities.
- The Chief Executive and Head of Governance perceive their roles as being accountable for the implementation of targets relating to providing access for all patients.
- The committee structure provides lines of accountability regarding provision of services / quality for disabled people. 56 committees, feed into 5 boards which then feed into the trust board – the terms of reference of 6 committees mention disability and of these 2 mention learning disability.
- There is no facility on the Patient Administration System to recognise patients with disabilities, though this will be available on a new data system due to be installed in late 2008.
- There was no response to an organisation-wide email asking staff about how they responded to, or worked with, learning disabled people.
- There are no dedicated systems in place when booking appointments or arranging discharges for people with disabilities, or specifically those with learning disabilities.

4.3 NOMINAL GROUPS: STAFF CONCENSUS OF ISSUES RELATING TO THE CARE OF PEOPLE WITH LEARNING DISABILITIES

4.3.1 Preliminary nominal group

For ease of reference, the preliminary nominal group will be referred to as NG1. This group was conducted in January 2008 as a session on the trust nurse induction programme in a room in the hospital's training and development centre.

4.3.1.1 Participants of NG1

Information about the participants of NG1 can be found in Appendix R4.1, which includes Table 4: Profile of participants of NG1.

4.3.1.2 Findings of NG1; consensus of participants

The following ideas were generated in response to the question: what challenges do we currently face when working with people with learning disabilities? Responses were recorded in rounds by going around the room and asking each participant to offer an idea which was then recorded on a flip chart. Three rounds had taken place when no further ideas were offered. None of the participants passed, but on several occasions, they affirmed ideas that had already been recorded. In total 27 ideas were recorded on the flip charts and after brief discussion in the group similar ideas were consolidated (with agreement being given by the participant who suggested the original idea). After consolidation, sixteen items remained (shown in Table 5) which were then scored by the participants. Only seven of the seventeen ideas (41%) received scores from the participants.

Consensus of agreement was reached about the seven most important challenges faced by the participants when working with people with learning disabilities. Usually in NGs, items with the lowest scores are eliminated but as ten of seventeen ideas received no scores, differences in these items could not be distinguished and therefore all ten of the un-scored items were eliminated. When offered the opportunity to add or re-rank the ideas, one participant stated that she was confident that the ideas she had scored

represented the most important challenges and that re-ranking would not alter her allocation of scores. All participants then stated that they agreed with her so re-ranking was not carried out. It was concluded, therefore, that consensus had been reached regarding identification of the most important challenges that nurses face when working with people with learning disabilities. The consolidated ideas and scores are presented in ranked format in Table 5 below, which also shows the thematic summary of each (used for thematic comparison with the results of the follow-up NG). In response to the question "What challenges do we currently face when working with people with learning disabilities?" consensus of opinion identified the most important challenges as being (in summarise form) difficulty with communication, time pressures and accessing specialist skills.

The facilitator documented her observations of the participants' behaviour and non-verbal communication at two points; during the five minutes that participants were given to consider and list their ideas, and at the end. At first, the participants appeared a little reluctant and uncomfortable, but they seemed to enjoy partaking in the NG after the silent ideas section had commenced. Several participants seemed apparently uncomfortable once again as the round robin exercised of collating ideas begun, but were visibly relieved when they realised they could pass on rounds of ideas. The participants were very compliant with the exercise and several stayed after the group (into a break time on the Induction Programme) to ask questions about learning disabilities.

Eight participants opted to complete the free comments forms that were distributed to all participants. This generated thirteen comments, ten of which reiterated ideas identified in the NG. The remaining feedback comments were:

- "We don't have enough understanding on how to deal with such patients and if we address this issue it would be a great leap forward"

- “This session has made me think about things. I don’t come across patients with learning disabilities very often but know I need to respond more appropriately”
- “All the points raised in the group are very valid. Unfortunately I think time is our biggest restriction. Good discussion”

The participants were provided with the facilitator’s contact telephone number and email in case they had any questions or concerns about the group of if they wanted copies of the report summarising the findings. At the time of writing, the facilitator had not been contacted by any of the participants. NG1 took a total of 63 minutes to administer.

Table 5 Consolidated ideas from NG1

Participant responses	Summary of idea	Total of scores	Rank
We have difficulties in communication (for example when a patient may not be able to describe what they need)	Difficulty with communication	72	1
We face time pressures – patients with learning disabilities may need more time to communicate	Time pressures	18	2a[6]
We do not sufficiently use skills of other members of the healthcare team and use MDTs more effectively when looking after people with learning disabilities	Accessing specialist skills	18	2b
We find it hard to involve patients sufficiently in their care	Involving patients	12	4
We need to get rid of their stereotypes and remember individuality / assumptions about a patient's ability may reduce independence	Dealing with stereotypes	6	5
We are over reliant on carers and need them to stay all the time to provide information	Over reliance on carers	6	6
We experience difficulties in ascertaining whether the patient understands what they have been told or in establishing the best method of giving a patient information	Checking the patient has understood	6	7
We face challenges of assessing patients effectively and forming care plans			
We can be affected by our patients not feeling comfortable in a hospital environment / clinical settings can further exacerbate communication difficulties			
We do not necessarily know how to access specialist learning disability services for skills / advice			
We would benefit from having a care plan / information from the patient's home/ community			
We can be affected by bureaucracy (e.g. targets in A&E not conducive to increased time needed for communication)			

[6] Some ideas were had joint rankings. In these cases, the rank has been split into a and b (but this does not indicate an order of priority as both were scored equally).

We do not necessarily have skills or experience to know how to deal with patients reactions / behaviour (for example, agitation, affection)			
We might fear dependency levels of patients with learning disabilities due to a lack of specialist skills			
We can face difficulties in conveying the complex needs of a patient with learning disabilities in nursing handover			
We are unsure whether it is acceptable to use carers to “speak for” patients/ how do nurses establish who is patient’s advocate			

4.3.2 Follow-up nominal group

For ease of reference, the preliminary nominal group will be referred to as NG2. This group was conducted in June 2008 as a session comprising part of the bi-monthly Nursing Sisters' Meeting.

4.3.2.1 Participants of NG2

Information about the participants of NG1 can be found in Appendix R4.2, which includes Table 6: Profile of participants in NG2.

4.3.2.2 Findings of NG2; consensus of participants

The following ideas were generated in response to the two questions:

Question 1: "Have hospital passports made a difference to how you work with patients with learning disabilities? If so, how?"

Question 2: "What challenges do we still face when working with patients with learning disabilities?

Responses to Question 1 were recorded in rounds using the same method as for NG1. Only one round took place in which ideas were recorded, and all participants then passed in the following round indicating that there were no new ideas. In total fifteen ideas were recorded on the flip charts; these were consolidated to eight (see Table 7) following a discussion in the group. As in NG1, the participants declined the opportunity to re-rate ideas, however the group concluded that they did not want to disregard any items as firstly, they felt they were all important and secondly because there were only eight ideas. Therefore agreement was reached about the eight most important ways in which passports have made a difference to nurses working with patients with learning disabilities. In response to the question "Have hospital passports made a difference to how you work with patients with learning disabilities? If so, how?" consensus of opinion showed that the three most important were with (in summarised form) understanding the patient's needs, gaining rapport and providing information.

Exactly the same process was repeated for Question 2. Twenty nine ideas were generated in three rounds, and after discussion, these were

consolidated to ten ideas. When offered the opportunity to add further ideas, two new ones were added that the group felt were individual and should not be combined with existing ones. In response to the question "What challenges do we still face when working with people with learning disabilities?" consensus of opinion showed that the three most important challenges were (in summarised form) understanding legal issues, identifying a single communication system and involving patients.

The participants of NG2 appeared used to group work and readily took on the task by silently writing their ideas. Throughout the session, three nurses had to separately leave the room to respond to bleeps. This is a real consequence of conducting group work in a work based environment, but as the staff were used to bleeps, it did not seem to have a disruptive effect. Some of the nurses seemed to be visibly moved having read the Death by Indifference (Mencap 2007) excerpt. This contributed to some very heart-felt group discussion, especially as one participant had worked at the hospital were one of the patients featured in the Mencap report had died. She explained to the group that although she had not been part of the team looking after the patient, the whole organisation had been affected by the investigation, publicity and the resulting changes in practice and policy.

Two participants opted to complete the free comments forms that were distributed to all participants; their comments were:

- "Passports seem like an excellent move forwards and will remove a lot of the frustrations / issues that have been faced recently".
- "Passports need to include information of how to cope with distressed or agitated patients".

The participants were provided with the facilitator's contact telephone number and email in case they had any questions or concerns about the group, though at the time of writing, the facilitator had not been contacted by any of the participants. NG2 took a total of 85 minutes to administer, which include the time taken for the ensuing discussion.

Table 7 Consolidated ideas from NG2 for Question 1

Question 1: "Have hospital passports made a difference to how you work with patients with learning disabilities? If so, how?"

Participant listed these responses / ideas	Summary of idea	Total of scores	Rank
understanding patient's behaviour, needs and routine to be able to create a therapeutic environment	Understanding patient's needs	63	1
gaining rapport with the patient	Gaining rapport	35	2
sourcing information and ensuring consistency / reliability of information (e.g. points of contact / where to start looking for further info)	Providing information	19	3
supporting compliance with intervention / treatment	Helping compliance	12	4a
allowing carers flexibility (e.g. re visiting – can stay / go realizing that patient's needs can be identified)	Flexibility for carers	12	4b
assessing patients needs for specific equipment / approach	Understanding equipment needs	9	6
understanding preferred method of communication (such as getting pens and paper for alternative communication)	Understanding communication method	9	7
Removing pressure of time required to initially assess patient	Reducing time pressures	9	8

Table 8 Consolidated ideas from NG2 for Question 2

Question 2: "What challenges do we still face when working with patients with learning disabilities?

Participant listed these responses / ideas	Summary of idea	Total of scores	Rank
Having awareness of legal issues regarding capacity and consent / knowledge of policy	Understanding legal issues	35	1
Needing to agree a single, appropriate way of communicating about patient with complex needs to eliminate scope for missing recommendations for treatment	Identifying single communication system	26	2
Remembering to involve / talk to patient	Involving patient	25	3
Having sufficient staffing levels to provide patient with stimulation and activity	Having sufficient staffing	14	4
Needing in-house / continuing professional development and training	Training staff	12	5a
Sharing the responsibilities for managing complexities of patient with learning disabilities with the multi-disciplinary team	Using MDT approach	12	5b
Using easy to understand communication (nurse to patient)	Using appropriate communication	11	7
Aiming for continuation of care staff (to reduce the number of nurses involved in the care of the patient)	Having same nurse	9	8
Managing other patients' reactions to patient with learning disability	Managing reaction of others	7	9a
Assessing understanding / checking we've been understood	Checking patient understands	7	9b
Understanding how we accommodate other disabilities	Understanding other disabilities	4	11
Overcoming previous bad experiences of looking after patient with learning disabilities	Overcoming bad experiences	3	12

4.3.3 Comparison of nominal groups

4.3.3.1 Comparison of participants of NG1 and NG2

The purpose of conducting nominal groups was to gather a range of opinions from staff about working with patients with learning disabilities. Participants of both groups were selected purposively to include qualified nurses working within the organisation; the samples were similar in size and each represented (averagely) 1.45% of the population of nurses employed by the organisation. The typical profile of a participant of NG1 is of a staff nurse (Band 5), aged between 20 and 29 years old with an average of 6.94 years of post-qualification experience. This is representative of "front line" nurses, who would be responsible for a considerable amount of the direct patient care on a ward. By contrast, the typical profile of a participant of NG2 worked at ward sister level (Band 7), aged between 40 and 49 years with an average of 17.02 years post-qualification experience. Tabulated and graphical comparisons of the participants of each group are available in Table 9 and Figures G and H.

Table 9 Comparison of participants of NGs

	NGT 1	NGT 2
Number of participants	23	28
Percentage of nurses employed by organisation (%)	1.3	1.6
Banding / designation		
Nurse manager	0	2
Band 8 (e.g. matron)	0	1
Band 7 (e.g. ward sister/ charge nurse/ clinical nurse specialist / practice educator)	2	18
Band 6 (e.g. junior sister)	3	6
Band 5 (e.g. staff nurse)	18	1
Age		
20 – 29 years	14	4
30 - 39 years	4	8
40 - 49 years	3	9
50 - 59 years	2	7
60 – 69 years	0	0
Years since qualifying		
Average years	6.94	17.02
Median years	3	14

Figure G Comparison of banding of participants of NGs

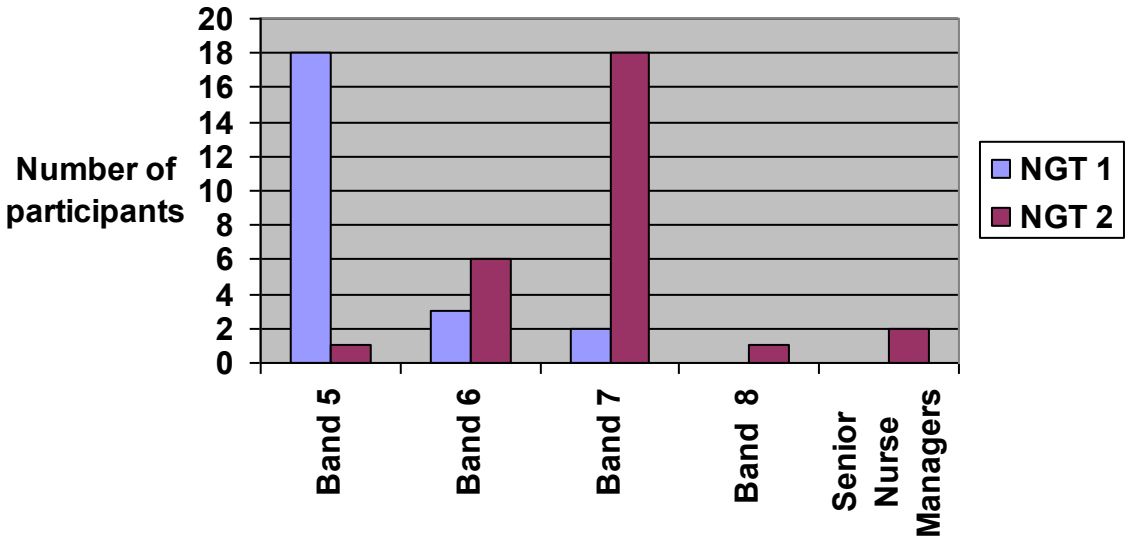
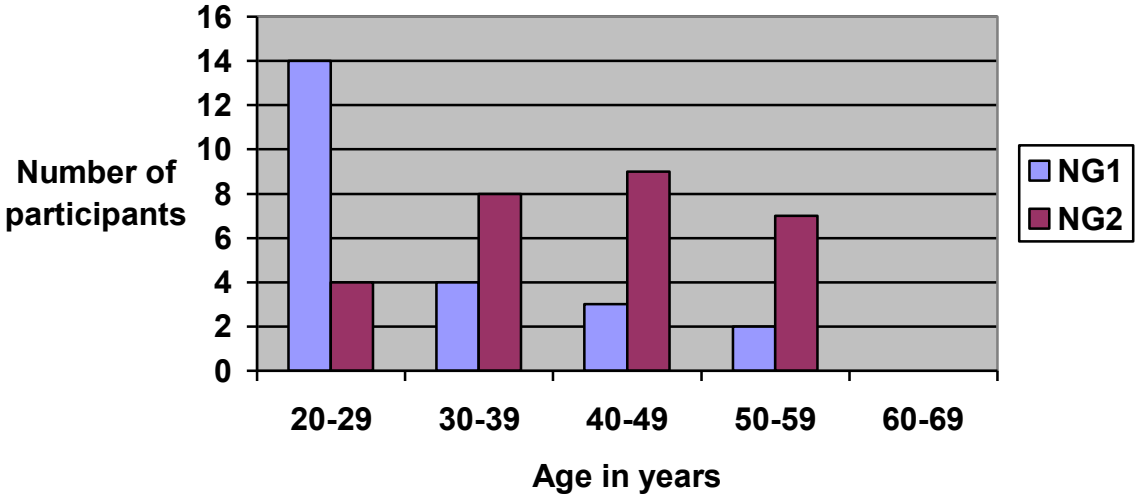


Figure H Comparison of age of participants of NGs



4.3.3.2 Comparison of the findings of NG1 and NG2

Due to the nature of data generated by NGs, responses from the participants defy direct comparison. Additionally, there does not appear to be any guidance about presentation of findings from NGs in the literature. However, by summarising each idea, themes can be identified and considered for grouping and comparison; these will be identified in the following section by their rank (as indicated in the corresponding tables) for example NG2, Q2,

Rank 1 refers to the idea ranked as most important, in response to question 2 in the follow-up NG.

In January 2008, twenty three qualified general nurses, who were mainly new to the organisation, reached consensus of opinion about the seven most important challenges that they faced when working with patients with learning disabilities. Six months later, in June 2008, twenty eight senior experienced nurses who had, or whose teams had, used the passport in practice with twenty patients, considered (in response to question 1) whether the passport had made a difference to the way they worked with patients with learning disabilities. These nurses identified eight ways in which the passports made a difference to the way they work with patients with a learning disability.

In NG1, the highest ranking idea was having difficulty in communicating with patients with learning disabilities. In NG2, the nurses identified three ways in which the passports had helped with communicating with patients. These included understanding the patient's needs (Rank 1), gaining rapport with the patient (Rank 2), providing information (Rank 3) and understanding the patient's preferred method of communication (Rank 7).

In NG1 the idea ranked second was facing time pressures when working with people with learning disabilities, due to more time being need to communicate and carry out treatment. By comparison, participants of NG2 stated that using the passport reduced time pressures (Rank 8).

Not knowing how to access specialist skills, such as learning disability nurses and speech and language therapists, was the third most important challenge identified by participants of NG1. Six months later, nurses (in NG2) stated that the passports helped with sourcing reliable sources of information and contacts (Rank 3), such as community healthcare professionals.

Dealing with stereotypes associated with learning disabilities was a challenge (rank 5) identified by NG1 participants. Specific examples given the by the nurses included having assumptions that a patient would be agitated, overly affectionate or non-compliant with treatment. Consensus reached by NG2 participants suggested that the passports could help to address this issue by provided information about a patient's behaviour and needs (Rank 1) as well as assisting with compliance with treatment (Rank 4a).

Finally, over-reliance on carers for information about a learning disabled patient was identified as a challenge by NG1 participants (Rank 6) whereas NG2 participants felt that the passports allowed more flexibility for carers (Rank 4b). Carers were not expected to stay longer than they wished as information about the patient was available in the passport.

Two ideas were common to both groups; these constituted challenges faced by the nursing staff when working with people with learning disabilities that were not perceived to be addressed by using the passport. The issues of how to confirm that a patient understands nurse to patient communication and involving patients in their care were identified in both NG1 and NG2 (in response to question 2).

Ten other ideas were agreed in response to question 2 of NG2: "What challenges do we still face when working with patients with learning disabilities?". These ideas had not been considered by nurses prior to the implementation of the passports five and a half months earlier (the interpretation of these findings is provided in the next chapter). These were:

- having an awareness of the legal issues of working with learning disabled people (Rank 1)
- identifying a single communication system for the multi-disciplinary team to record patient interventions / recommendations (Rank 2)
- having sufficient staffing levels to provide appropriate care for patients with learning disabilities (Rank 4)

- needing training about learning disabilities (Rank 5a)
- using a multi-disciplinary approach to providing care for people with learning disabilities (Rank 5b)
- using easy to understand communication, such as having accessible information available to give to patients (Rank 7)
- being able to ensure continuation of nursing care for learning disabled patients (reducing the number of new people that the patient would need to get to know) (Rank 8)
- managing other patients reactions to a patient with learning disabilities (Rank 9a)
- understanding other disabilities (Rank 11)
- overcoming previous negative experiences of working with patients with learning disabilities (Rank 12)

Other comparisons between the groups, not relating to consensus of opinion, have been outlined in appendix R4.

Summary of Nominal Groups

- In January 2008, 23 qualified nurses took part in NG1and reached consensus of opinion about the most important challenges that they faced when working with patients with learning disabilities.
- Six months later, in June 2008, when twenty learning disabled patients had used the passport, consensus of twenty eight senior experienced nurses suggested that the passport had made a difference to caring for patients with learning disabilities.
- Of seven challenges initially identified, the hospital passport was considered to have addressed five. The remaining two ideas represented ongoing challenges for the nurses as they had not been addressed by the use of the passports.
- Following the implementation of the passports, ten previously unidentified challenges emerged from NG2 suggesting that staff awareness had increased about working with patient with learning disabilities.

4.4 Evaluation of patient experiences

Patient feedback regarding experiences of using the hospital was collated in June 2008 using semi-structured interviews, based on eight questions formulated by the Project Overview Team. A form (Appendix M8) was used to record the responses during interviews conducted by nurses of the community learning disability teams covering two primary care trusts. Of the twenty patients (purposively sampled due to having learning disabilities and forthcoming elective admissions to hospital) who used the passports between January and June 2008, sixteen agreed to meet with the learning disability nurses to complete the interviews. Four patients were not asked due to being considered (by the learning disability nurses) to be too ill or due to still being in hospital. Of the sixteen patients, fourteen lived in the locality of the hospital's local primary care trust and two lived in the locality of a neighbouring primary care trust. All of the interviews were conducted in the patients' usual residence; eleven in the patient's own home and five in a residential / group home. Two patients completed the interviews with a nurse independently, ten were conducted with the support of their carers and four interviews were conducted by the patients' carers (in both cases, these were formal carers from a residential home). The results of each interview question are presented in Appendix R5 and limitations of the instrument are acknowledged in the Discussion chapter.

Additional feedback was received in the early stages of the passport implementation, from a nurse who had helped one of the patients to complete a passport. Although this patient was later considered to unwell to take part in the evaluation, the nurse reported her impression of the passport having visited the patient in hospital. She wrote:

> *"Recently a service user was admitted to XX ward. She has a friend who is also a service user and he told his mum, who had attended the hospital passport launch. As a result this service was contacted and asked if someone could get involved to help make sure care was appropriate.*

I helped carers to fill in a hospital passport and shared it with a ward sister …., as well as the nurse who was caring for the service user at the time….. When carers from her home went to visit they were really pleased to learn that the staff …. had read the hospital passport and were using the information inside.

For example, staff knew that the service user is a fan of [a pop singer] and that she is scared to sleep in the dark. Because of this, her light had been left on at night and people had chatted to her about [the pop singer]! The carers felt she would find this especially comforting as it was her birthday yesterday, and staff had noted that too.

The carers have asked if they can have some hospital passports in the home. This is so that they can fill in sections with service users, so that they just need to be brought up to day if someone needs to attend hospital on an emergency basis or as a planned admission, and so that service users feel they have ownership."

Summary of evaluation of patient experiences

- Twenty patients used hospital passports between January and June 2008. Of these, sixteen took part in semi-structured interviews with learning disability nurses.
- In all cases, the passports were used on admission.
- 14 responders reported that they had found the passport helpful.

4.5 CHAPTER SUMMARY

In this chapter I have outlined the findings of the various stages of the project; the organisational review, the baseline data, the nominal groups and the evaluation of patient experiences. Whilst the data from diverse sources defies direct comparison, I have endeavoured throughout this chapter to present it in a format that is easy to understand, that supports interrogation as well as highlighting its limitations.

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

This was an exploratory project aiming to find out if an initiative to support communication for people with learning disabilities could raise staff awareness of the needs of this specific group of patients. It is the intention of this chapter to interrogate the findings outlined in the previous chapter (Chapter 4: Project findings) within the context of current knowledge and the scope of the project. In turn this aims to highlight the potential contribution that this project can make to the knowledge base. This chapter has been divided into two sections; firstly interpretation of the findings and secondly reflections and critical analysis of methodological issues.

5.2 INTERPRETATIONS OF THE PROJECT FINDINGS

5.2.1 Revisiting the project questions

In order to establish the context and value of the project findings, it is useful to revisit the three original project questions (outlined in Chapter 3). It has been said that this approach can help to prevent issues of researcher bias:

> *"Structuring the findings around the research questions will ensure that the student does not make the mistake of falling in love with the data"*
>
> (Brown 1996, in Perry 1998: webpage)

5.2.1.1 What were the challenges that staff identified when working with people with learning disabilities (at the start of the project)?

Information regarding the first project question was gathered using the nominal group technique (NGT). At the start of the project, consensus of staff opinion identified seven interrelated challenges related to working with people with learning disabilities. The reason for the group assigning scores to only 7 ideas out of the available 17 can only be speculated upon. The process of identifying ideas was not anonymous, in fact one of the benefits of the NGT is that it is acclaimed as being democratic by offering all participants a chance to speak. It avoids the risk of the group being dominated by one larger personality or a more senior participant, as can happen in focus

groups. However, as the participants selected and scored their ideas individually, the social desirability effect (French et al, 2001) that relates to peer pressure, would not apply to the scoring and consequent rating of ideas. Therefore, it can be suggested that consensus was concentrated and agreement was reached readily. Perhaps the focus of the participants on a small number of ideas is what Bartunek and Murningham (1984) meant when they wrote that the NGT confines its findings to a well defined and pre-formulated idea.

The challenges identified by the participants were:

- difficulty with communication
- time pressures
- accessing specialist skills
- involving patients
- dealing with stereotypes
- over-reliance on carers
- difficulties in checking the patient has understood.

These findings cannot be thematically grouped due to their small number and the fact that they arose from only one nominal group (NG) carried out at that time (at the start of the project). However, by comparing them with the existing knowledge base, it is possible to establish whether the findings serve to strengthen what is already known or whether they have, indeed, identified previously unreported issues. The challenges identified by the participants of the preliminary NG constitute many of the barriers to healthcare for people with learning disabilities previously outlined in the literature review that informed this project (see Chapter 2). The overarching source of the majority of the challenges facing staff is well documented as being a lack of knowledge, sometimes self identified, about learning disabilities (Hogg 2001 and Lennox et al 1997). In fact, staff confidence levels deriving from knowledge has been found to be lower regarding learning disabilities than other types of disabilities (McConkey and Truesdale, 2000).

To explore the effects of this lack of knowledge of healthcare professionals, it is useful to refer to a valuable diagrammatic representation by Sowney and Barr (2006). This diagram has been selected as it consolidates themes from existing literature regarding the experiences of healthcare professionals (such as McConkey and Truesdale 2000, and Slevin and Sines 1996 as outlined in Chapter 2) as well as the outcomes of Sowney and Barrs' (2006) study involving focus groups with accident and emergency nurses. An adaptation of this diagram (see Figure L) shows how the findings of this study reinforce what is already known about the challenges facing general nurses working with learning disabilities. The original authors identified four areas related the lack of knowledge of nurses; reduced competence, overreliance on carers, passive caring role and fear/vulnerability. It is suggested that five of the challenges identified by participants of NG1 (namely difficulties with communication, not understanding how to access specialist skills, having stereotypes about learning disabilities, involving patients and difficulties in checking the patient has understood) can be attributed to the issue of reduced competence of the nurses. Another of Sowney and Barr's (2006) areas, over-dependence on the patients' carers, was also identified by the participants of NG1.

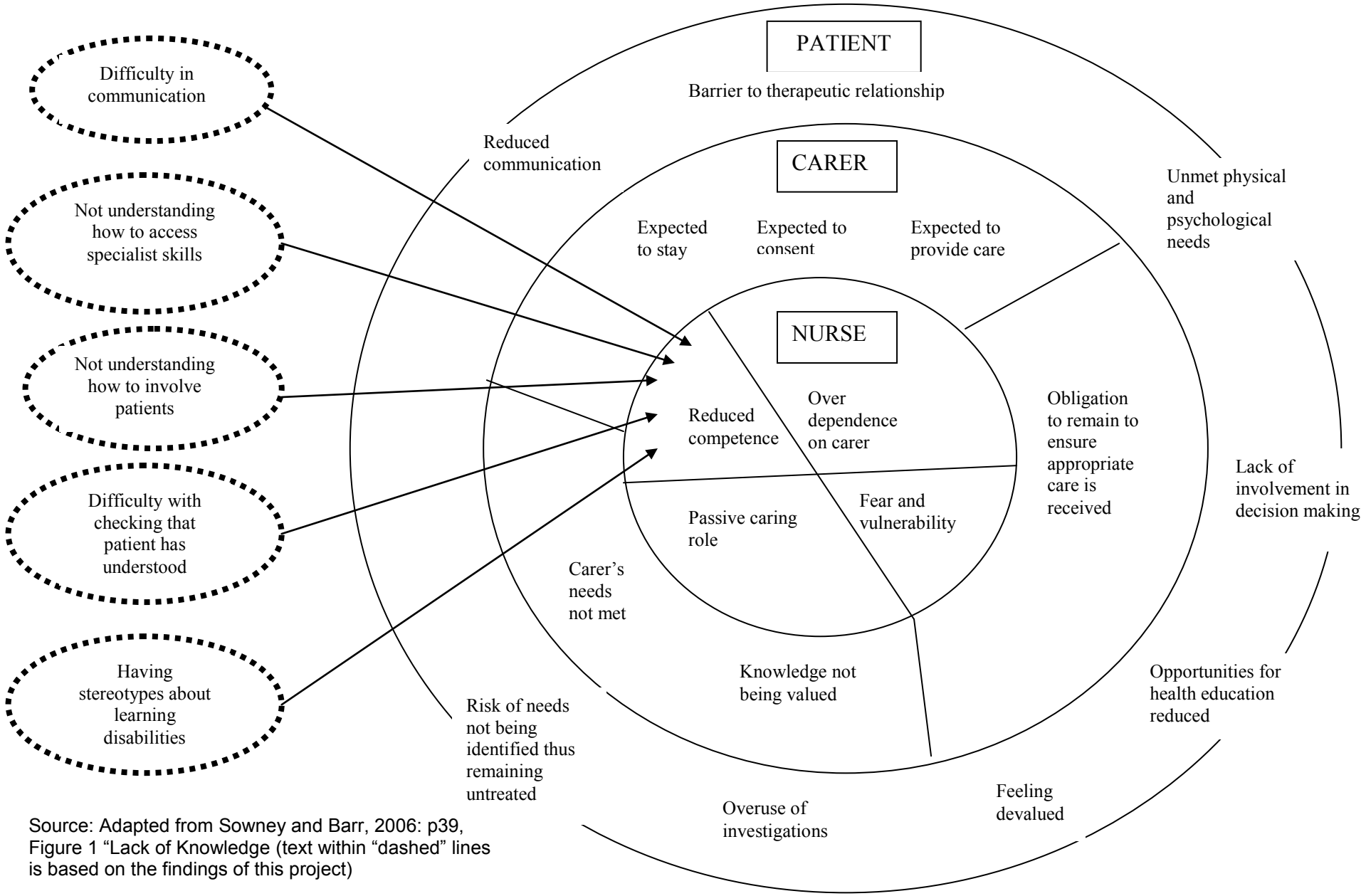
The final challenge identified in the preliminary nominal group was that of time pressures. Whilst this cannot be considered as an area of knowledge, it impacts the nurses' ability to provide effective and inclusive care. This effect has been noted previously, though seemingly only in relation to time constraints facing general practitioners (Lennox et al 1997, Hogg 2001 and Alborz et al 2005). To expand on this point, it is useful to draw out one of the lost items generated in NG1 (that is, an item that was disregarded in the consensus development process). The point was made by an accident and emergency nurse, who observed that the targets imposed on services to respond to patients within a given time frame (in A&E all patients should be discharged, transferred or admitted within four hours of arriving at the department, DOH, 2000b) can contradict the increased time that may be needed to communicate with a learning disabled patient. This has

implications for policy development regarding the accessibility of general healthcare services for people with learning disabilities.

The findings of the preliminary NG showed that local circumstances reflect the wider national and international picture. The project findings showed that nurses taking part in NG1 had similar perceptions and experiences to those of healthcare professionals previously reported in the literature. Time pressures affecting the way that general nursing staff work with learning disabled people, was an area that appears not to have been previously covered in the literature. Davis and Marsden (2001) point out that one of the biggest barriers to improving staff attitudes is a lack of awareness among staff that improvements are needed and the perception that patients' needs are being met when they are not. The nurses taking part in NG1 however, demonstrated insight into their shortcomings in this area by clearly identifying seven challenges they felt they were facing.

It can be concluded that the first project question (What were the challenges that staff identified when working with people with learning disabilities (at the start of the project)?) was effectively answered.

Figure L: The consequences of lack of knowledge on the experiences of nurses, carers and patients with learning disabilities



Source: Adapted from Sowney and Barr, 2006: p39, Figure 1 "Lack of Knowledge (text within "dashed" lines is based on the findings of this project)

5.2.1.2 Can the use of hospital passports improve the patient experience?

The second project question sought to evaluate patient experiences of using the hospital passports. There is little to compare the finding of this aspect of the project to due to the limited evidence base relating to the experiences of people with learning disabilities when using general hospital services. However, ineffective communication by healthcare staff has been linked to patient perceptions of exclusion, being ill-informed and having a fear of treatment (Hart 1998, Cumella and Martin 2004, Scott et al 2005).

Sixteen interviews were carried out by learning disability nurses with patients (and / or their carers) who had used hospital passports during an admission between January and June 2008. Encouragingly, in all cases, the passports had been used at the time of the patients' arrival on the wards, and were given to the nurses to provide essential information about the patient. It was not asked, and would have been useful to know, if the patient initiated showing the passport to the nurses or whether the nurses asked to see it. If the nurses had asked the patient for their passport, this could have shown that staff were aware of a new procedural approach to the providing care for learning disabled patients.

Service users perceived the passports as documents to give to healthcare providers (for example, "I showed it to the nurse and the consultant"). It is difficult to ascertain the level of understanding that the patient / carer had regarding potential benefits of using the passport, or in other words, whether they had insight into the potential for the passport to improve the relationship between the patient and nurses and to ensure that their needs were identified / met. A case example (in the form of a letter from a learning disabilities nurse) shows that the use of the passport led to the needs of a patient being met. It was felt that the patient was more comfortable in hospital as a result of the nurses having, and responding to, information about the patient's preferences (such as having a light on at night).

Information about the influence of the passports on the patients' experiences was elicited via two questions. Firstly, when asked if the passports had made a difference to the care received, nine patients / carers (56%) responded that it had.

This question did not elicit explicit information on which aspects of care were affected, such as the quality of care, patient / nurse communication or resulting health outcomes; a need for further investigation is therefore identified. The concept of cause and effect is complex to convey and measure, particularly when conducting research with people with learning disabilities (the issues of working and conducting research with learning disabled service users are explored later in this chapter). Secondly, when asked if the passport had been helpful, fourteen positive responses (86%) were received (the other two responders were not sure). The responses indicated that passports improved the patient / nurse relationship ("It helps people to get on with me"), supported communication ("It showed people what was wrong with me") and provided a single source of information ("Everyone knew where to look to find out about me"). Additional positive feedback was provided by some patients / carers who added (when asked if they had any other comments), that staff were aware of how to use the passports and that the passports would be of benefit to other learning disabled people.

Valuing people (DOH 2001) anticipated that the use of health action plans would improve the patients' experience and resulting health outcomes. Patient -held communication tools have been applied, though not extensively, in different formats, such as the health log (Curtice and Long 2002), health action plan (Howatson 2005) and health toolkit (Hunt et al 2006). None of these studies, however, have reported the patients' perspectives. Therefore, while the sample size of this element of the project was small, the evaluation of patient experiences and an additional case example indicate that the passports positively affected the experience of people with learning disabilities when using hospital services. It is difficult to draw conclusions from this data, particularly those that were generalisable, but it does provide an insight into how the passports are perceived by the patients/carers and suggests that the patients /carers view them as a tool to support information giving and communication from the point of admission. The need for further investigation into the effect of using patient held communication tools, such as the hospital passport, on the patient experience is recognised and its implications for practice are outlined in the following chapter (Conclusion).

5.2.1.3 Can hospital passports increase the awareness of staff in an acute setting caring for people with learning disabilities?

The third and final project question looked at whether staff awareness of learning disabilities improved as a result of working with patients using the hospital passports. Nurses in the follow-up nominal group identified challenges relating to their role that continued to exist despite the implementation of the hospital passport within the organisation. It is suggested that, having worked with patients using the passports, the nurses developed their awareness of learning disabilities. This in turn enabled them to identify other issues or aspects of care, in the form of new ideas that had not been previously conceived during the preliminary nominal group five and a half months earlier. There are, however, several variables that need to be considered in relation to the rise in staff awareness. It should be noted that nurses of the follow-up group were more senior and experienced than those in the first group and therefore could have had more insight into issues relating to the care of people with learning disabilities (this is explored in more depth in Section 2 of this chapter). Additionally, there could have been a general increase in awareness of learning disabilities across the organisation due to launch of the passports as a new initiative.

The most important issue for nurses was the need to understand legal issues regarding learning disabled patients. The participants demonstrated some awareness of the need for services to be accessible to all patients, though legislative responsibilities under, for example, the “Disability Discrimination Act” (OPSI 1995) or the “European Human Rights Act” (Department for Constitutional Affairs, 1998) were not specifically referred to. On the other hand, the “Mental Capacity Act” (OPSI 2005) was mentioned several times with reference to concerns about how to establish a patient’s capacity to consent. This supports the lack of familiarity and confusion amoung nurses regarding legislation governing the care of people with learning disabilities that has been noted previously in the literature (Sowney and Barr, 2007 and Cumella and Martin, 2000).

Nurses identified the need for a single, appropriate way of communicating with colleagues about patients with complex needs, to eliminate scope for missing vital information and recommendations for treatment. This point referred to the fact that

a patient may be seen by numerous members of the healthcare team (doctors, nurses, therapists) from several organisations (hospital, primary care trust, social services), all of whom may record their observations in professionally, or organisationally specific documentation systems. Participants of NG2 also highlighted, as a separate point, the challenge of sharing the responsibilities for managing the complexities of a learning disabled patient with the multidisciplinary team. Curtice (2002) supports this, stating that by promoting shared responsibility amongst healthcare professionals, health outcomes in people with learning disabilities can be optimised. A tragic case example (used as a stimulus for generating ideas in the nominal groups) demonstrating the consequences of ineffective multidisciplinary communication is provided in "Death by Indifference" (MENCAP, 2007), in which the death of a patient (Martin) was attributed to a lack of communication within the healthcare team. One of the participants recounted, to the group, her experience of working at the Trust that had been responsible for providing care to this patient at the time of his death. Whilst the nurse had not had direct involvement with the patient, she described the devastating effect that high profile death and ensuing investigation had on herself and her colleagues. This had left her fearful, she said, of working with learning disabled patients in case she "failed them". This discussion could have explained the consensus of opinion identifying the need to overcome previous negative experiences of working with learning disabled patients. Whilst the issue of negative experiences does not seem to have been the specific focus of any previous research, several sources suggest that biases, assumptions and stereotypes are held by nurses about patients with learning disabilities (Godsell and Scarborough, 2006 and Sowney and Barr 2006). Even in the absence of personal experiences, it is evident that the experiences of colleagues, examples receiving media attention and those described in professional or educational materials could shape staff opinion and lead to the development of unhelpful preconceptions. The positive effect of the passports on the experience of patients have been discussed above (in section 5.2.1.2); it is hoped that continued experience or working with patients using the passports will provide positive experiences of working with patients with learning disabilities for staff.

Access to training and development about learning disabilities was highlighted and nurses specified that ongoing initiatives to raise awareness would be more effective than one off sessions / study days in changing culture within the organisation. This reflects the essence of "A Health Service of all Talents: Developing the NHS Workforce" (DOH 2000), which calls for a radical change in education, culture and philosophy to make the NHS workforce more responsive to the needs of patients and the diverse demands on the service. The need for training and development is well supported in the literature; a lack of confidence and competence in nurses is likely to be attributable to the lack of education (Brown 2005) or experience of learning disabilities, both professionally and socially, in healthcare professionals (Slevin and Sines 1996, Sowney and Barr 2005, McConkey and Truesdale 2000). The need for continuing professional development and training about learning disabilities was ranked as the (joint) fifth most important issue by nurses of the follow-up nominal group; the implications of this finding are addressed in the following chapter (Conclusion / Recommendations).

Several findings arose regarding the practical and resource implications of improving service delivery to people with learning disabilities. The group recognised that continuation of staff (i.e. having the same nurse dedicated to caring for a patient whenever possible) could lead to improved communication and rapport between nurse and patient. It was recognised that this in turn would require increased staffing levels, which would of course, have resource implications such as funding bank/agency nurses or including managers, who are usually super-numerary, in the staffing levels on a ward. In the current health service climate, there is an ever-present need for service developments to be achieved through cost neutrality, or at least with minimal demand on resources. As an alternative to increasing the number of staff on a ward Davis and Marsden (2001) piloted and evaluated the effectiveness of having one Clinical Nurse Specialist (CNS) dedicated to supporting the needs of people with disabilities (not specifically learning disabilities) across a hospital. Benefits of the CNS role were noted as improved preadmission communication and reduced anxiety for the patients, as well as an increase in staff awareness levels of disabilities. Although this initiative had its own cost implications, these were divided across the hospital as a whole as the CNS post was a generic resource. In the absence of additional funding, it may

be possible to improve staff awareness and patient experience through closer partnership working with specialist community services, such as learning disability teams. However, this would require further investigation as the absence of existing evidence demonstrating the effectiveness of such facilitative input has been acknowledged (Alborz et al, 2005).

Issues identified before and after the implementation of the passports suggest that they remain to be challenges that have not been met through using the passports. Two such ideas were found; confirming that a patient understands nurse to patient communication and involving patients in their care. Whilst these issues are important to consider as part of an approach to improving access to people with learning disabilities, it can be concluded that they do not represent an increase in staff awareness of these issues (because they did not arise as a result of the implementation of the passports). The identification of ideas in common between nominal groups taking part in consensus methods is a technique applied by Carney et al (1996), who reinforce that an idea is not new as it has been considered previously.

Findings relating to this project question have informed the recommendations for policy and practice outlined in the following chapter. In sum, these concern:

- the identification of a single, appropriate way of communicating about patients with complex needs, such as learning disabilities
- multidisciplinary collaboration within the hospital teams and effective partnership working with staff with specialist skills, such as community learning disability nurses
- training and development opportunities for staff to develop their knowledge of learning disabilities
- practical and resource implications of improving service delivery to people with learning disabilities.

5.2.2 Other findings of the project

It is recognised that other findings have emerged from the project that do not necessarily fit into the categories of the original research questions categories.

Information generated in pursuit of some of the project objectives has been outlined below.

5.2.2.1 Did the hospital passport address the challenges identified by nurses relating to working with learning disabled patients?

Comparisons between the findings of NG1 and NG2 can be drawn by thematically linking the two sets of data; these can be used to demonstrate how the passports helped to individually address the challenges facing nursing staff. A full comparison of themes and ranked ideas is outlined in the previous chapter (see section 4.3.3.2), but the following example is offered here by way of explanation of this point. The issue of knowing how to access specialist skills, such as learning disability nurses and speech and language therapists was ranked in NG1 as the third most important challenge facing nurses. Having experienced the passports in practice, over a five and a half month period, participants of NG2 described how the passports helped with sourcing reliable sources of information and contacts.

Whilst this project did not set out to measure the perceived effectiveness of the hospital passport, the fact that nurses were able to report ways in which the passport had made a difference to their practice provides an encouraging platform from which further research can be launched. This would address a gap in the knowledge that exists regarding the effectiveness of patient-held communication tools from a care-provider's perspective.

5.2.2.2 What is the profile of patients with learning disabilities? Looking at the baseline data

One of the project objectives was to establish baseline data about service users with learning disabilities using the hospital services. An analysis of the data provided a profile of learning disabled service users, which supported statistics previously reported and enabled a comparison with the wider population of service users. The data needs to be viewed with certain issues of data quality in mind; these have been fully outlined in the Methodology chapter and discussed further in section 5.3.

The number of learning disabled patients using hospital services in 2005/6 and 2006/7 period was 584. This represented 0.3% of the total number of patients, which reflects the national average of people learning disabilities in the population of 0.23-0.29% as estimated by Whittaker (2004). However, it has also been recognised that these figures are likely to be an underestimation of the true number of patients with learning disabilities, which means that prevalence rates suggested by BILD (2004) of 1-2% may be more likely.

The most common primary diagnoses of patients with learning disabilities using the hospital related to dental medicine, neurology and cardiovascular medicine, which supports national data reported by the Foundation for People with Learning Disabilities (2006). The accuracy of the diagnoses contributing to this diagnostic profile of service users are discussed below (see section 5.3.3.2 below). The average age for patients with learning disabilities was lower (exactly half for 2005/06) than for the total population as would be expected due to the shorter life expectancy generally associated with learning disabilities (DOH 2001). The ratio of male to female patients for people with learning disabilities (27:23) was converse to the total population of patients (24:26) but reflective of the estimated national learning disability figures, which ranges between 1.2:1 for severe and 1.6:1 for mild learning disabilities (First Initiatives, 2008).

It can be concluded that the profile of patients with learning disabilities using the hospital was representative of data collated nationally. One of the project aims was to meet the needs of a sector of service users and thus the baseline data contributed considerably to the project rationale.

5.2.2.3 How does the hospital provide services for patients with learning disabilities? Looking at the organisational approach

One of project objectives was to carry out an organisational review of policies, processes, roles and responsibilities in place in the hospital regarding the care of people with learning disabilities. Not only did it provide a starting point from which to launch the project but it investigated the underpinning approach to delivering services to disabled people, and specifically those with learning disabilities. In an analysis of the concept of equity of access, Sowney and Barr (2004) suggested

that one way of establishing the inclusivity of a service was through an examination of policies and protocols. As no previous evidence of organisational policy reviews relating to disabilities was identified in the literature, a framework for conducting this stage of the project was adopted from literature in the field of economics.

Of 244 organisational policies, 9 referred to disabilities or vulnerable people and only 2 mention learning disabilities. References to learning disabilities were notably absent from the organisation's strategy documents, terms of reference for committees and there were no dedicated processes (such as appointment booking) or systems (including IT). Therefore, whilst the organisation claims that overall it is committed to equity of access for all patients, it does not appear to identify a need to respond to particular support needs of certain groups of patients. In addition, no responses were received to an inquiry to staff about working with patients with learning disabilities, on the electronic hospital bulletin board that usually generates high levels of feedback, which could indicate either a lack of awareness about learning disabilities or a lack of interest in an initiative focused on learning disabilities. Finally, a procedural capacity for patients to slip through the net was identified in relation to appointment booking and discharge arrangements. If patients did not attend or rearrange an appointment, responsibility lay with the patient's GPs to convey that this could be due to a disability (for example that the patient might not be able to read or understand a hospital letter). However, as was explained in the Introduction chapter, not all cases of mild learning disabilities are even diagnosed at primary care level and therefore a major failing in the system was noted. The process of discharging a patient from a ward, including the liaison with community agencies, would be dependent on the information contained in the patients nursing, medical or multi-disciplinary notes. If none of these sources stipulated that a patient had a learning disability or that the patient was known to the Learning Disability Team in the community, then adequate support structures may not be in place when the patient leaves hospital.

The need to raise the profile of learning disabilities and develop policies in this area has been called for on several occasions (Godsell and Scarborough 2006, Corbett 2007). The provision of healthcare, as a public service, is governed by legislation such as the "Disability Discrimination Act" (OPSI 1995), the "European Human

Rights Act" (Department for Constitutional Affairs, 1998) and the Mental Capacity Act (OPSI 2005). These should ensure equity of access for all patients, including those with learning disabilities, though the Disability Rights Commission, (2006) state that enforcement of these acts is required in order to ensure that organisations have usable policies in place, and that these policies are adhered to. A series of recommendations for the organisation have been outlined in the following chapter.

5.2.3 Summary

Although the interpretation of findings was found to be complex, the findings of the project do lend themselves to being summarised. To recapitulate what has been learnt from this project, it is useful to review one of the project aims which was to address gaps in knowledge relating to the people with learning disabilities using general hospital services. An essential component of a doctorate project is the provision of evidence of theory building, which in turn can lead to a reconceptualisation of problems (Perry 1998). A summary is provided (using an approach employed by Sowney and Barr, 2006: p 42), of what is already known about this topic and what this project findings add to the knowledge base (see Table 10 below). The implications of the project findings, relating to policy, practice and further research, are covered in the conclusion.

Table 10: Summary of existing and new knowledge

What is already known about this project: • People with learning disabilities face barriers when accessing general hospital services. • Difficulties in communication are the source of many barriers. • From a patient's perspective this can result in feelings of fear and being marginalised. • Carers are frequently over-depended on as sources of information and communication. • Lack of knowledge results in low levels of confidence and competence in general nurses caring for people with learning disabilities (though levels are higher in those with previous experience or educations of learning disabilities). • There have been a limited number of Initiatives to improve communication using information tools.
What the project findings add to the knowledge base: • Hospital passports were found to be effective in addressing many of the challenges identified by general nurses regarding working with people with learning disabilities. • Hospital passports improve the patient's experience of being in hospital and contribute to the patient feeling more involved. • Staff awareness of the issues relating to caring for learning disabled patients can be raised by working with patients using hospital passports.

5.3 REFLECTIONS AND CRITICAL ANALYSIS OF METHODOLOGICAL ISSUES

5.3.1 Introduction

This chapter aims to discuss the effectiveness and limitations of the project design and therefore address whether the methodologies and methods used were effective in eliciting information to address the research questions. In turn, this aims to promote optimal confidence in the project findings and in the subsequent recommendations (see chapter 6). Issues that were considered in the planning stage of the project are outlined in the Methodology chapter, but the consequences of the decisions arising from critical consideration and reflexivity of issues of rigour are addressed below. In the final section, reflections are offered on the decision of the Local Research Ethics Committee and its implication for recommendations for future work.

5.3.2 Choice of project design and research process

I adopted a mixed method approach because it lent itself particularly well to the exploration of the experiences and opinions of groups of patients and nurses, whilst being able to incorporate supporting numerical data. The epistemologically constructionist viewpoint contributed to the meaning-making of my observations of how social phenomena develop in certain contexts; for example, the development of stereotypes amoung nurses regarding learning disabilities and service users' feelings of being involved in their care. The project's design was able to reinforce and build upon the knowledge base outlined in the literature review and respond to the legislative drivers (also outlined in Chapter 1). Case studies are particularly suitable for establishing an evidence base before any changes are made to policy and practice (see Methodology section). In some ways, this is similar to grounded theory which (in very simple terms) aims to wholly derive theory from the project findings. However, in reality, Barbour (2001) warns, ethical approval and funding would be difficult to achieve without an evidence base emerging from a literature review. Therefore, the case study of a service development, offers a slightly less rigorous but far more adaptable methodology. I found the adoption of an constructionist / interpretivist stance particularly useful in extracting themes from the project findings and for developing recommendations for practice; the transition

from research to practice being, of course, an essential component of a work based project.

Limitations of the project and its findings are predominantly identified in the following section looking at issues of rigour, but two, in particular, relate to the research design. Firstly, a pilot study was not conducted during the planning stage of the project, and therefore a prior opportunity was not created to identify potential problems that could have arisen regarding data collection. Trochim (2003: webpage) advises researchers to obtain:

> *"….feedback from your respondents regarding how easy or the measure was and information about how the testing environment affected their performance"*

It is difficult to speculate on issues that could have been raised through a pilot, but it is acknowledged that reliability of the instruments (the questions and procedures used in the nominal groups and the semi-structured questionnaire) could have been strengthened or supported if a pilot had been carried out. Pilot testing a nominal group was found to be particularly effective by Carney et al (1996) who found that it highlighted several pitfalls, such as the importance of clarifying terms being considered in order to prevent deviation from the subject being studied (e.g. they found that "resource" is open to varying interpretations, contexts and meanings). It can be suggested, therefore, that this could be an important way of ensuring that the right project questions are identified at the outset in order to collate optimal data.

It is likely that conducting a pilot of the patient evaluation would have flagged up the limitations in data gathered by the learning disability nurses conducting the semi-structured interviews. It could be argued that an experienced researcher could have pursued more in-depth and useful responses during the interviews, than perhaps healthcare professionals without research experience. Having a researcher conduct the interviews could also have addressed the potential influence of staff perceptions of learning disabled patients' communication. In Purcell, Morris and McConkey's study (1999), it was found that perceived

competence varied from patients' actual communication ability. Within the context of this study, the interview responses could have been affected by this variable. .

Another benefit of conducting pilot interviews with patients could have highlighted the need to adapt the questions used. These were agreed by the project overview team prior to any interviews being conducted and therefore the restrictions of using closed questions were not realised. For example, the wording of Question 4 (see Appendix R 5) could have been changed from "Did the passport make a difference to the plan of care and treatment provided?" to "Do you think using the passport made a difference to what happened in hospital? If so, how". This open question could have been used by an experienced researcher to explore the patient's opinion of the effect that the passport had on their hospital journey.

The inclusion of comparison groups in the research design may have helped to reinforce / contradict the findings. Importantly, they could also have been used to highlight the existence of any causal relationships (see section 2.3.3 below); for example, a comparison group could have included NG participants that had worked in the organisation but had not had experience of the working with patients using the passport. This could have identified the existence of a variable in the form of changing organisational culture (i.e. a general awareness following the launch of the passports rather than specific awareness having worked with a patient using a passport). In light of this, it would, have been impossible to have had a control group of nurses who had not been exposed to the intervention or changing organisational culture (Parshuram and Kavanagh, 2004).
Similarly, having a pilot group of service users could have also addressed the same variable. Additionally, it would have been interesting to investigate the effect of previous experience of learning disabilities among the nurses (as has been previously reported by Slevin and Sines 1996, Sowney and Barr 2005, McConkey and Truesdale 2000 – see section 1.1.3 of this chapter) on staff awareness. This information could have been used to separate nurses into groups to investigate the awareness of staff a) using the passports but with no previous experience of learning disabilities and b) staff with previous experience of learning disabilities but with no exposure to the passports.

Despite the acknowledgment of limitations, the project design was considered to be an appropriate and effective way to investigate the project questions, particularly within the scope of a work based project of this size. There are a number of related recommendations for practice and further research that have been outlined in the following chapter.

5.3.3 Issues of rigor

All research is selective in that it is impossible for the researcher to literally capture truth. However, the proximity of our findings to the truth can be increased by critical consideration of issues of rigor. The following section discusses several approaches to optimising rigor, though it is necessary at all times to remain weary of Barbour's (2001: webpage) warning:

> *"The uncritical adoption of a range of technical fixes (such as purposive sampling…. triangulation and respondent validation) do not, in itself, confer rigor".*

I have aimed to convey the following section as clearly as possible and to do so it was important to first clarify the terminology used. Traditionally, and particularly in quantitative research, the terms validity and reliability have been used. However, there have been calls from some authors for a reconceptualisation of some research terms in relation to qualitative research. Examples of proposed alternatives include the concepts of "dependability" (Lincoln and Guba 1985, page 300), "consideration of researcher bias" (Norris 1997) or "trustworthiness, rigor and quality" (Golafshani, 2003, page 604). As this project used a combined approach, I have opted to base the structure of the following section on Mays and Pope's (1995) comprehensive account of strategies for improving rigor, covering sampling, ensuring reliability and safeguarding validity.

5.3.3.1 Sampling; addressing selection bias

A description of sound sampling techniques is essential for the rigor of a project to be established (Barbour, 2001). This project aimed to understand social processes (staff awareness and patient experience) and whilst it involved some numerical data it was not concerned with the statistical representation offered by probability

sampling. Purposive, or theoretical, sampling is a subtype of non-probability sampling and it offers researchers an approach to addressing issues of selection bias that can arise with other types of non-probability sampling. Its purpose is:

"To identify specific groups of people who …possess characteristics…. relevant to the social phenomenon being studied"

(Mays and Pope, 1995: webpage)

The first nominal group was held with attendees of the nurse induction programme, and the second with nurses attending a sisters' meeting. (The sampling methodology has been outlined in the Methodology section). Whilst the accessibility of the participants was important, the decision to use these groups of staff was not made purely on the base of ease (known as convenience sampling). The participants were all qualified nurses, working in a general hospital and therefore either experience of working with learning disabled patients or the potential to develop experience (both perspectives were important). Trochim (2006: webpage) describes this as expert sampling, a type of purposive sampling that "involves the assembling of a sample of persons with known or demonstrable experience and expertise in some area". Purposive samples need to indicate, in some way, a representation of the wider population being studied. Thus, whilst the sample sizes were small (23 participants in NG1 and 28 in NG2), they represented approximately 1.45% of nurses within the organisation and ranged in age, experience and seniority. It could be suggested that whilst the consensus of opinions may not be generalisable of all nurses in the organisation, or on a wider scale nationally, they do provide insight into issues facing nurses working with learning disabled patients in an acute setting.

It was not possible to replicate the sampling methodology used in the preliminary nominal group when conducting the follow-up group (see Methodology). However, comparing longitudinal changes in consensus of nurses in the organisation was achieved by initially working with nurses attending the induction programme and later with nursing sisters. As described in the Methodology chapter, ward sisters work at the interface of strategic and practical healthcare provision. Therefore, whilst they may not be directly involved in as many patients as staff nurses, due to their managerial responsibilities, they are accountable for the leadership of these

nurses and thus should be in touch with issues facing members of their teams. Additionally, ward sisters usually have considerable post qualification experience, which includes of course, working at the "frontline" delivering care. Therefore the participants of NG2 would have also based their opinions and resulting ideas on their own experiences of working at staff nurse level and above; their expertness in these areas is the reason that they were purposively sampled for the groups.

Patients were also selected purposively to take part in the semi-structured interviews, as the inclusion criteria stipulated that they had a learning disability and had used a passport during an admission to hospital within the timeframe of the project.

5.3.3.2 Ensuring reliability

In simple terms, reliability refers to the repeatability or replicability of a measurement (Kirk and Miller 1986). In other words, if another researcher used the same methods and analysed their findings in the same way, they would yield the same outcomes. However, in reality it is not as straightforward as this, particularly when it is appreciated that reliability can only ever be estimated as it is a composite of true values as well as (systematic or random) error (Trochim, 2006b). As a researcher, it is essential that we overcome the temptation to simply confirm our beliefs, which is why Spencer et al (2003) said that the explicit recognition of bias can be as important as eliminating it. It is for this reason that I have outlined in detail the factors affecting reliability of the project findings.

Data quality

There are several issues relating to the quality of the baseline data generated by the Information Development team regarding the number of service users with learning disabilities. This project identified that the reliability of the data was dependable on learning disabilities being included as one of the patient's diagnoses. Learning disabilities may not have been the reason why a patient attended at the hospital and therefore may not have been recorded, even though it was an important part of the patient's medical history. This raises the issue of diagnostic variation that could exist depending on the skills of the doctor treating the

patient; one doctor may record the fact that a patient has a learning disability, whereas another may not. This issue was the subject of a study by Iezzoni et al (1992) who observed, in their review of the discharge data of 162,790 patients on a hospital data system that bias existed against coding chronic or co-morbid conditions (such as learning disabilities).

Further complications were due to the existence on the data system of 109 codes relating to learning disabilities. This meant that if the staff recording the patient episode (such as an appointment) on the data system noted that the patient had a learning disability, they would need to select one of the codes. The accuracy of the baseline data therefore was reliant on the data imputer's awareness of learning disability and the different conditions that could be associated with it.

The issue of diagnostic variation again needs to be considered when considering the quality of the baseline data; this time with reference to the differences between the diagnoses of people with learning disabilities and the total population of patients. The reasons for the variations (shown in Table 2) are not certain, though the most common diagnoses affecting people with learning disabilities (such as dental and neurological problems) reflect the evidence base relating to the prevalence of medical conditions affecting people with learning disabilities FPLD 2006). However, the fact that there are three of the ten most diagnoses affecting people with learning disabilities are related to dental problems whereas none of the ten most common diagnoses affecting the total population relate to this area of medicine. It could be suggested that this diagnostic variation is too significant to simply attribute it to fact that people with learning disabilities are prone to dental problems. In fact, the dental consultant is known throughout the organisation to be a champion for learning disabilities, which could be the reason for conscientious, well-informed coding by him and his department about episodes involving patients with learning disabilities.

Despite the limitations acknowledged, it is still suggested that the baseline data provided as current and accessible information as possible about all patients using the hospital. A snap-shot study of service users in a particular clinical area could have been an alternative approach, though this could have posed severe logistical problems as it would not have been possible to conduct such an exercise within the scope of the project, predominantly due to the time limitations.

Procedural reliability

It could be argued that conducting the research outside the researcher's own organisation would improve reliability as the researcher would be unaffected (or less affected) by micro politics or the internalised rules, described as "instincts, constructs and mental models" by Plesk and Greenhalgh (2001: webpage). However, the nature of work-based learning means that the researcher can have ready access to key individuals / information as well as understand the specifics of the organisation (such as the committee structure used in the organisational review see Methodology). Most importantly, the insider researcher is ideally placed to drive the recommendations arising from the project and consequently affect change that might be necessary. Therefore the benefits of working within my own organisation were considered greater than the associated threats to reliability.

Reliability of analysis

The reliability of the interpretation of a project's findings is prone to investigator bias, which can occur when one interviewer who is aware of the outcome variable(s) is responsible for collecting and analysing data. This can be addressed by blinding the researchers to the variable(s) or a less rigorous approach involves applying inter-rater reliability estimates (where two or more raters work on the same dataset). However, whilst both approaches reduce the risk of bias and therefore improve the reliability of the findings, they also have considerable resource implications and consequently were not considered for this project.

Retest reliability describes an approach to estimating reliability in which the same test is administered to the same sample on two different occasions. In practice, estimators such as this are resource-intensive and this in turn can have real-world implications particularly within the scope of this work-based project which is time limited and un-funded. However, there are guidelines that can be systematically and conscientiously followed to improve reliability, even in the absence of applying an estimator itself. The main way researchers can ensure the equivalence of retest reliability is by meticulous record keeping (Mays and Pope, 1995). Consequently, I have strived to produce a detailed and unambiguous report that essentially distinguishes between the analytical framework and interpretation of the data, in order that another researcher could hopefully come to the same conclusions (providing they analysed the data in the same way).

5.3.3.3 Safeguarding validity

This section identifies how strategies to promote, or safeguard, the project's validity have been employed. However, before embarking on an explanation of these, it is necessary to be mindful of the plethora of opinion regarding issues of validity in both qualitative and quantitative research. On one hand, several types of validity are generally associated with quantitative research and these need to be considered in order to ascertain the overall quality of a study and its findings. The overarching types are, in very simple terms: conclusion validity (which aims to establish whether a relationship exists between the study variables), internal validity (which looks what causes this relationship), construct validity (which focuses on whether the study carried out what it intended) and external validity (which is concerned with the extent to which the findings can be generalised to a wider population and / or setting) (Trochim, 2006). On the other hand, the primary aim of qualitative researchers is to seek "illumination, understanding and extrapolation to similar situations" rather than generalisation (Hoepfl 997, cited in Golafshani, 2003, page 600). Therefore it can be assumed that "qualitative research almost exclusively limits itself to 'internal' generalisations" (Maxwell, 1992, in Winter 2000: webpage). This work based project focused on one organisation

only; reviewing its policies and practices, developing a picture of its service users and investigating the effects of the hospital passport on the staff and service users. In reality, whilst the findings may be of wider use or national interest, claims of generalisation of the findings are very limited.

The key to safeguarding the validity of the project findings, therefore, lies in the extent to which these findings can be strengthened. Triangulation is an approach to validation, in which evidence is gathered using a variety of methods to address a research question. This is not a new approach and recognition of its advantages seems to date back to the middle of last century. With reference to work based projects Jick (1979: p 602) observed that:

> *"Organizational researchers can improve the accuracy of their judgements by collecting different kinds of data bearing on the same phenomenon".*

Triangulation is usually thought of as mixing quantitative and qualitative methods, but is also possible to employ different methods within the same methodological approach. In this case, an action research methodology was applied in the investigation of the impact of the hospital passports and several approaches to triangulation serve to strengthen the resulting outcomes. Firstly, the research methods used included nominal groups and a semi-structured interview. It is not possible to directly compare the data emerging from the different methods, but it can provide reassurance in the findings in the form of corroboration; this is described as across-method triangulation (Begley, 1996). For example, the passports were found to increase staff awareness of learning disability and the positive effect of the passports was reinforced by an improvement in patient experience demonstrated by semi-structured interviews and a case study. Secondly, within method-triangulation was used to strengthen the findings of the nominal groups. In other words, the two data sets generated from the one method (i.e. the ratings and the free comments generated by the nominal groups) served to reinforce each other (Begley, 1996). Thirdly, a further triangulative approach was offered in the presentation of the findings; in Chapter 4, a narrative summary of the findings was combined with some quantification and graphical representation of the

findings. Mays and Pope (1995) suggest this is can help to make the findings more readily intelligible, which ultimately serves to improve the overall rigour of the research.

An alternative concept to triangulation is offered by Janesick (2000) who suggests that the term crystallisation is more useful. In principle, crystallisation acknowledges that the objects of a study, the participants, are variables in themselves and therefore subject to complexity and change (like crystals). The responsiveness of the methods selected, therefore, is key to the production of credible findings. This is of particular importance to a work based project in which the researcher is working in their own organisation as the suitability of the data collection tools is likely to govern the overall outcome of the project. Plesk and Greenhalgh 2001: webpage) agree, stating that:

> *"It is often better to try multiple approaches and let direction arise by gradually shifting …attention towards those things that seem to be working best….. [and to] explore new possibilities through experimentation, autonomy and working at the edge of knowledge and experience"*

An example of this in practice was the decision to use the nominal group technique to gather staff opinion as it was felt that a questionnaire or audit approach to gathering information about staff awareness would not have been positively received within the organisation.

5.3.4 Reflections on the decision of the Local Research Ethics Committee

This project was carried out within the researcher's professional remit as Patient Information Manager. The design, implementation and evaluation of hospital passports needed to be conducted within the organisation. It was identified as the focus for the doctoral project because it met the requirements for work based learning at Level 5; it enabled me as the researcher to conduct a vocational project whilst employing and building on rigorous research and project management skills. However, it is a programme requirement to "embed [one's] work within a personal,

organisation and ethical framework" (Work Based Learning and Accreditation Unit, 2006: page 13) and for this reason, it is necessary to reflect upon the Research Ethic's Committee (REC) to consider the project as "service evaluation" as opposed to "research" and therefore to waive the requirement for full ethical approval.

The National Research Ethics Service (NPSA, 2009) outlines the ethical requirement for establishing whether a project should be classified as research, service evaluation or audit. It explains that ethical advice from a REC must be sought if the project involves patients or service users. However, whilst the Research Governance Framework for Health and Social Care (DOH 2005) exists to reduce the unpredictability of REC decision making processed and outcomes, it stops short of stipulating that all projects involving service users constitute research. This perhaps can be cited as the reason for variations in the advice and decisions generated by RECs identified in Angell et al's (2007) systematic study of REC procedures, which noted considerable inconsistencies including those concerning the care and protection of participants. To counteract any discrepancies in REC decisions and to reduce the amount of time and resources spent on REC applications, van Teijlingen et al (2008; webpage) call for waivers to be give to all "non-invasive low-risk studies such as face-to-face interviews …. on non-sensitive topics".

In the event of a REC waiver, accountability and transparency are, perhaps, even more important. Stalker (1998) recommends that organisations set up a research advisory group for health service projects involving people with learning disabilities, the membership of which should ideally include service users. With reference to this project, this role was fulfilled by the Project Overview Team (see Appendix M1.1) which discussed and carefully considered, for example, issues of informed consent, data protection and interagency governance procedures.

The LREC decision to waive ethical approval had both advantages and disadvantages. A major benefit was that primary data collection could start much sooner than if it had been necessary to await REC approval. However, a drawback of not having full ethical approval means that careful consideration will need to be

given when preparing this a summary of this project for publication. For this reason, it is likely that elements of this project will be reported rather than the project as a whole. Ethical issues associated with service user involvement will not need to be addressed, for example, by focusing on interagency collaboration to improve access to an acute hospital for learning disabled patients or the effectiveness of the nominal group technique for measuring changes in awareness levels.

5.4 Summary

It has been said that:

> *"If you self-consciously set out to collect and double check findings, using multiple sources and modes of evidence, the verification process will largely be built on the data gathering processes and little more need be done than to report on the procedures"*
>
> (Miles and Huberman 1984, p235)

With this in mind, I have paid particular attention in the production of this report to explain the research limitations as well as the implications of the decisions made throughout the course of the project. By identifying that the methodologies and methods were effective in eliciting information to address the research questions, I have aimed to promote understanding of, and confidence in, the project findings and in the recommendations outlined in the following chapter.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

6.1 Summary of project

This project was carried out in recognition of four premises that were supported by a review of the literature and associated evidence, which were:

- patients with learning disabilities have poorer health outcomes
- this group of service users are known to experience difficulties when accessing healthcare
- barriers to healthcare include lack of competence and awareness about learning disabilities of staff working in general hospitals
- initiatives to improve access generally require further investigation.

The project was underpinned by an organisational review which showed that, despite legislative guidelines regarding accessibility and equity for all service users, very few policies or procedures were in place to respond to the needs of people with learning disabilities. A profile of service users with learning disabilities, developed through an investigation of patient data, showed that local information reflected national data regarding prevalence of learning disabilities and other characteristics (such as medical problems, average age and gender). Therefore the need to respond to issues facing people with learning disabilities was no less important locally than in other areas.

This project aimed to look at the potential influence of hospital passports on staff awareness of learning disabilities and on patient experience of using hospital experiences. Over a six month period, twenty patients used hospital passports during an admission to hospital. The nominal group technique was used for longitudinal comparison, to show that the passports helped to address many of the challenges that nurses identified when working with learning disabled patients. Consensus of staff also suggested that their awareness of learning disabilities had increased as a result of working with patients using passports. Semi-structured interviews with patients showed that patients felt that the passports were helpful during their admission to hospital and in some cases had improved the care they had received.

The cyclical nature of the action research methodology adopted for the presentation of this project report, meant that the process lends itself well to consideration of the next steps. Having planned, actioned, evaluated and reflected on the project stages so far, the process recommences with the planning of recommendations that can in turn be actioned and so on. A considerable amount has been written about getting evidence into practice, succinctly described by Nutley et al (2003: p125) as moving "From Knowing to Doing". However, in a work based project, implementation of the "doing" element is already underway and therefore consideration is given in this section to how this can be disseminated, sustained and transferred. With reference to reflexivity that is crucially embedded in a work based project, particularly one that is based on an action research framework, it is essential to consider "what will I do, or do differently, as a result of my involvement with this project and as a result of its findings?". It is intended therefore that the recommendations outlined below demonstrate what has been done, is being done and will be done due as a direct result of this project.

6.2 Dissemination of project findings

Dissemination has been described as "the mechanism for pushing research information out" (Nutley et al, 2003: p126) and is important for several reasons. Providing feedback to those involved in the project helps to recognise the contribution they have made to developments in the knowledge base and highlights the effect that it can have on potential service outcomes. Notwithstanding issues of transferability at this stage, it is also important to pass on the story so far to a wider audience such as professional colleagues and other researchers as this process can be used to formulate plans for future research, changes in practice and plans for sustainability. In fact, one could even go as far as stating that it is the researcher's ethical responsibility to express the teleological benefits of research, that it, the advantages of the project to the community and society (Iphofen, 2004).

Considering the project stakeholders helped to determine the approach to disseminating the project outcomes. Feedback to service users is currently being led by the learning disability nurses through the Access to Acute groups

that they facilitate. These groups are held in various localities for service users and their carers, as well as by advocacy groups, and look at issues of overcoming barriers to accessing general hospital services.

Within the organisation, I am jointly conducting with other members of the Project Overview Team a series of presentations (see Appendix C1 for an outline of the sessions) to groups and committees whose remits are pertinent to issues of access for people with learning disabilities. These include the Patient Information Group, the Patient Issues Group, Vulnerable Adults Committee and the Diversity and Human Rights (see Appendix R2 for the full committee structure). Probably the most important part of the presentations involves the group/committee considering how to respond and they were asked to pledge (or negotiate) one way in which they would implement a change (for example the Patient Issues committee are driving a review of the discharge policy to include protocols for the patients with disabilities, including those with learning disabilities). It is recognised that the key to successfully embedding improvements in practice and policy within the organisation depends on strategic / executive recognition and support. Webb and Rogers (1999: p 500) recommend that the backing of the chief executive, inclusion in the organisation's strategic plans and "gentle nagging" provide the best combination to driving forward developments. Delivering presentations that covered the committees that constitute the organisations management structure is probably the most effective way of achieving this.

The importance of disseminating the core findings of the project to professional community is also recognised. Colleagues in the fields of learning disabilities, patient information, healthcare management and health policy development will be informed through sharing of information at networking meetings and by the intended publication of findings.

6.3 Sustainability of developments

The following section outlines steps that have been taken to promote the sustainability of the project outcomes in order to protect against the "improvement evaporation effect" (Modernisation Agency, 2002; p9).

6.3.1 Continued use of passports

Hospital passports were considered to improve the experience of people with learning disabilities using hospital services, both from a patient and nurse perspective. The baseline data gathered for this project showed that averagely 292 patients with learning disabilities use the hospital every year (based on figures for 2005/06 and 2006/07). Twenty patients were identified by the learning disability nurses as having forthcoming admissions to hospital. Even allowing for a high number of emergency admissions (for which it would not be possible to predict and prepare with a hospital passport), the need for more patients to have passports is still recognised. The learning disability nurses will therefore continue to identify, from their / their team's caseloads, patients requiring passports for forthcoming hospital admissions. In addition, plans are in place to upload the passport on to a new website promoting the accessibility of healthcare services for people with learning disabilities (www.easyhealth.org), which means that service users and carers will be able to download the passport themselves and complete it in preparation for an admission to hospital.

The effectiveness of passports needs to continue to be evaluated. Whilst the semi-structured interviews proved to be useful in eliciting patient opinions it could also be suggested that introducing another method of data collection would serve to strengthen findings once again through across method triangulation. Discovery interviews could be useful, particularly as they have been found to develop in-depth understanding of patient needs (Modernisation Agency, 2003).

The Project Overview Team will continue to convene to work on the outstanding issues as outlined above. Originally, learning disabled service users declined to form part of the team and expressed a preference instead to be involved as correspondence members, by working with the learning disability nurses to give their feedback on the work of the group and the development of the passports. However, several service users have now expressed an interest in being part of the team which is due, perhaps, to seeing positive outcomes in the form of the

passports and improvements in nursing care. This ultimately means that future work can move from the "expert advisor" model, which is staff led towards the "partnership" model, based on patient empowerment (NHSIII 2008: page 12).

Based on patient feedback, a few amendments need to be made to the passports such as replacing the diagrams with photographs (such as of medical staff and parts of the body).

6.3.2 Training and development for nursing staff

One of the ideas to emerge from the nominal groups with nurses was the identified need for training and education about learning disabilities. We know from the literature reviewed for this project that previous education about learning disabilities leads to increased levels of confidence and competence amoung staff. A training session for new staff has been introduced on the Nurse Induction Programme (subsequent cohorts to participants of the nominal group), which will reach about 500 nurses per year (all new members of nursing staff as well as those changing positions within the organisation). These hour-long sessions are being delivered by a rotating member of staff from the community learning disability teams as well as a learning disabled service user and cover awareness of patient communication issues, how to support people with learning disabilities and how to recognise/use the hospital passport.

For existing (rather than new) nursing staff, evidence suggests that continuing education is a more effective approach to improve professional practice and patient outcomes (NHS Centre for Reviews and Dissemination, 1999). Consensus of opinion of the nurses of the follow-up nominal group also called for continuing education rather than one-off training, which suggests that the benefits of this approach are recognised by healthcare professionals. However, there are many educational demands on healthcare professionals (for example, the need to maintain mandatory training levels on subjects such as resuscitation) and therefore it is important to plan and target training interventions to ensure they are as effective as possible. Collaborative work with the community learning disability teams (such as shadowing) is likely to constitute a successful way forward, particularly as dissemination of specialist

skills and knowledge is part of their remit and therefore there would not be a cost implication for this approach to interagency work. However, Reed and Vakola (2006) advised that conducting a training needs analysis (TNA) should be perceived as a crucial tool for achieving organisational change and therefore a preliminary meeting has (so far) been held with the Director for Training and Development.

6.3.3 Addressing practical issues of caring for people with learning disabilities

Several practical implications of improving service delivery to learning disabled patients emerged from this project. Whilst it is recognised that continuity of staff and increased staffing levels would be advantageous to both nurses and patients, the budgetary implications are obviously restrictive in today's NHS. For this, strategic and financial commitment is necessary at executive level, which is one of the reasons that dissemination of the project findings is so important (see section 6.2). However, there is a multitude of inexpensive / cost-neutral changes that can be made that will immediately improve the accessibility of healthcare for people with learning disabilities and make things easier for those providing it. For example, for ways to improve communication have been offered by Godsell and Scarborough (2006) and tips and suggestions for improving the accessibility of services have been compiled by the Disability Rights Commission (2004). A successful change in culture however, will be dependent on the articulation of a plan for implementation. This has yet to be formalised but the Project Overview Team proposes that a system of priority is developed to identify departments that need to develop responsive action plans to address how they will meet the needs of disabled people, including those with learning disabilities. For example, a number of complaints have been received by the hospital about the outpatient waiting areas. A meeting has been scheduled with the Outpatient Sisters, the general manager for the services, members of the Estates and Capital Projects team and importantly a member of the Project Overview Team. By using the recommendations for good practice (noted above) a plan for implementation should include the development of the waiting area to include a quiet zone in which patients who are very anxious or agitated (such as those with learning disabilities) can wait.

6.4 Spreading good practice: looking a transferability of project findings

The transferability of project findings must be considered in order to ensure that the lessons learnt from this project are not lost and in doing so, it is useful to consider the following adage:

> *"Great improvements occur in parts of the organisation, but the learning does not spread naturally"*
>
> The Modernisation Agency (2002: p9)

The scope for spread of good practice resulting from the project findings are numerous and have been addressed below.

6.4.1 Spread to other staff groups

A decision was made by the Project Overview Team in the early stages of the project to focus on the interface between nurses and service users with learning disabilities. Attention therefore must be paid to other staff groups to ensure that good practice is not just confined to care provided on the wards. Many members of the healthcare team, both qualified and unqualified, come into contact with learning disabled patients and could therefore benefit from using the passport. For example, reception staff could benefit from understanding a patient's preferred method of communication. The training needs of staff across the organisation as a whole will be included in the TNA currently being planned.

6.4.2 Spread to other hospitals and healthcare organisations

Whilst considering the cross-organisational implications of the project findings, it is important not to overlook inter-professional learning needs. The spread to other staff groups has been addressed above (see section 6.4.1) but the transferability of the findings to nurses working outside the acute sector needs also to be taken into account. Training and development aimed at the interface of primary and secondary care has been recognised as contributing to seamless patient care (Werrett, 2001 and Hibberd 1998). Therefore, once the training needs of the staff within the acute trust have been analysed (see section 6.3.2), consultations with the Head of Nursing for the Learning Disability Nursing Service of the local teaching PCT are proposed to establish the potential for joint development and education programmes.

With reference to the implementation of the passport, the work of the Project Overview Team was confined, for the duration of the project, to the acute hospital. It is intended though that a hospital passport will be patient-specific rather than organisation-specific and that the passports will be accepted across agency / organisational boundaries (i.e. if a patient was admitted to another local hospital they could take their passport with them). Therefore a wider working group incorporating leaders from neighbouring hospitals and primary care trusts has just been established. The group has set a vision to develop one passport that will be implemented across healthcare organisations in south west London by the end of 2008.

6.4.3 Spread to other service users

An underpinning perspective (based on a quote from a service user) of this project was that getting things right for people with learning disabilities means that you get things right for a lot of people. By improving access for people with learning disabilities, other groups of patients that could benefit are those with other disabilities, people who do not speak English as a first language, people with expressive or receptive communication difficulties and patients who experience “double barriers” (Alborz et al 2005: p178) such as disabled people from ethnic minorities. In fact, an example of transferability of the findings resulting from preliminary dissemination has lead to a pilot study of a communication tool for patients of the Multiple Sclerosis Service. However, an ultimate goal of the Project Overview Team is to coordinate the responses to improving access for these different groups of patients. Whilst recognising that they may have very unique needs, the development of a generic hospital passport that could be used by any service user is likely to ensure optimal acceptance in relation to organisational culture.

6.5 Conclusion

The justification for the award of a work based doctorate qualification is the delivery and execution of a programme that will achieve excellence in practice as well as the production of “original work that results in significant innovation and change within a profession and/or organisation.. [by recognising] the wider

political environments associated with innovation and …. and [implementing] strategies to achieve sustainable change" (Module Handbook 2005/6: Projects). Ultimately, the desired outcome of the programme is to be able to enhance the effectiveness of my role as Patient Information Manager and increase the contribution that I can make to my organisation and profession. It is hoped that the final chapter addressed ways in which the project findings have been used to achieve considerable service developments. These in turn, have resulted in improvements in the experiences and outcomes for patients and staff and will hopefully positively affect practice in other areas due to the potential for transferability of the findings.

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[8] There are actually two “British Journals of Learning Disability” (hence the publisher has been specified here).

Appendices

APPENDIX M1.1

PROJECT OVERVIEW TEAM

The project overview core team comprised members of staff at the hospital with a special interest in learning disabilities, including the Patient Information Manager (author), a nurse from an acute (orthopaedic) ward and a Preoperative Assessment Sister (both whom represented frontline clinical staff), the Deputy Director of Nursing (who is the organisation's Privacy and Dignity champion) and the Equality and Human Right's Manager. The team members had all been involved in previous work carried out within the organisation (led by the author) to raise awareness of the needs of people with learning disabilities when using acute healthcare services (Glaysher, 2005). Both the Patient Information Manager and the Deputy Director of Nursing also sat on a Safeguarding Vulnerable Adults Committee, an interagency group working across acute and community health organisations and social care providers.

The group also included learning disability healthcare professionals based in the community; their expertise was essential in order to gain an in-depth understanding of both the needs of service users with learning disabilities and also to understand the issues that this patient group face when making the transition from primary to secondary care (and back again). The community based element of the project work was facilitated by the Head of Nursing for Learning Disabilities from the local teaching primary care trust (PCT), who was also a member of the Learning Disability Partnership Board, a strategic interagency group working across geographical areas locally to improve and monitor statutory services for patients with learning disabilities. Other members included a nurse from the local primary care trust learning disability service and two nurses from a neighbouring primary care trust learning disability service (to promote equality and awareness across local services as well as networking and sharing practice)

Service users with learning disabilities were involved at every stage of the project, predominantly by the learning disability nurse manager who consulted and informed service users and their carers regarding, for example, the

proposals for the project and the timeframes involved. Users were invited to join the Project Overview Team but they declined, stating that their preference for involvement would be to contribute by liaising with the learning disability nurses. The design of the hospital passport was service user-led and it passed through four draft stages in development following suggestions and amendments made by service users and carers. As well as consulting individuals, community and advocacy groups (such as a local performing arts group whose principle members have learning disabilities) were also involved regarding the design of the passport and invitation of service users to complete passports in preparation of a hospital admission.

APPENDIX M1.2

ROLE OF THE RESEARCHER

I had previously led a major project to improve access to the hospital for people with learning disabilities (Glaysher 2005). Whilst many of the recommendations from the project appeared to remain in place (e.g. learning disabled service user involvement on the Site Signage and Access Committee), I felt it was necessary to regenerate enthusiasm in order to promote the momentum of ensuring improved access for patients with learning disabilities. My remit as Patient Information Manager goes beyond the production of leaflets, videos and CD-ROMs for patients; it involves the promotion of access to services through information (including patient held communication) and encompasses the issue of using information to support decision making, including informed consent.

I initially arranged a meeting with the Deputy Director of Nursing as I felt her role and commitment as the Privacy and Dignity Champion and membership of the Safeguarding Vulnerable Adults Committee lent itself well to the issues of equity of access for people with learning disabilities. It was essential to the success of any project to have Senior Nurse Manager Involvement as nurses constitute the largest staff group within the hospital (and the wider NHS) and the nursing dissemination structure is felt to be the most effective route for spread of information and instigation of service improvements.

I outlined two main ideas; firstly that I felt we needed to know more about the level of staff awareness of learning disabilities within the organisation and secondly that I knew from background reading of a communication tool had been piloted in Gloucestershire to support learning disabled patients when using healthcare services. We held a preliminary meeting with the Head of Nursing for Learning Disabilities from the PCT and a follow-up meeting with key staff was then held (the staff who attended this meeting continued to be members of the project overview team).

Since then I have been responsible for planning the project and have led the evaluative elements (all except the aspects directly involving service users) as well as jointly driving the project forwards . The group itself did not develop formal terms of reference initially (I am currently working on these at the time of writing), but instead opted for a task and finish approach (set a goal, set a date or measurement (e.g. number of patients) by which to achieve the goal and review it). Equally, the roles within the group were not formalised from the outset as it was felt that the group was small enough and sufficiently outcome focused that responsibility for each goal would be agreed as part of the goal setting process. I was responsible for all the hospital based work, which included conducting the organisational review, establishing the baseline data, conducting the secondary data collection and coordinating / facilitating the nominal groups. The passports were developed by the team as a whole, although the learning disability nurses led the service user consultation that underpinned this process. The Head of Nursing for Learning Disabilities coordinated the production of the passports as he held a small amount of funding. The learning disability nurses also conducted the patient evaluation interviews. Staff training to inform staff of how to recognise and use the passports was conducted by the Deputy Director of Nursing or myself (a shared responsibility due to part time hours). The responsibility of chairing meetings was alternated between myself, the Deputy Director of Nursing and the Head of Nursing for Learning Disabilities. Other responsibilities such as the production of minutes, sharing information (such as with colleagues at other hospitals) and investigating good practice examples (such as by contacting MENCAP) was shared unsystematically between members of the Project Overview Team.
The production of the final operational report will be jointly conducted by myself and the Head of Nursing for Learning Disabilities in order to promote the widest scope for professional and interagency credibility (even though it will largely be based on this project report). This report has been solely prepared and written by me.

APPENDIX M1.3

PROJECT STAKEHOLDERS

The primary stakeholders for this project include service users, such as patients, parents, carers and members of the public (as potential service users) as having potentially improved care outcomes. Both external (including advocacy groups, voluntary and community organisations) and internal stakeholders (for example, hospital staff in all departments) also stood to benefit from the end products of the project. The hospital management team was identified as a stakeholder group due to the advantages of being able to strategically demonstrate a response to the drivers outlined above. Finally, the outcomes of the project would inform the work of the professional community including those working in the field of learning disability (including the Independent Inquiry into Access into Healthcare for People with Learning Disabilities, IAHPLD 2007) and patient information networks (e.g. the national Patient Information Forum).

APPENDIX M1

SECONDARY DATA COLLECTION

There are numerous sources providing guidance for conducting quality literature searches in order to generate relevant, reliable and topical search outcomes. Ultimately, though, maintaining a current personal knowledge of literature searching strategies is paramount due to the fact that technological advances in the management of library systems (such as databases of journals, policy and statistics) are so rapid that many guides (such as Cooper 1998 and Hart 2001) appear out of date at the time of going to print.

Using Athens (a database interface and access management system) searches were undertaken using the following eight medical, healthcare and social science databases:

- BMJ Journals which covers all the journals within the BMJ Publishing group.
- BNI (British Nursing Index) a database that covers more than 250 nursing journals.
- Clinical Databases (Datastar) which involves access to medical, nursing and health management bibliographic databases.
- JAMA (Journal of the American Medical Association and archives)
- National Library for Health (NLH) encompassing NHS library and information services specifically aimed at NHS staff and users. This was also used as a portal to searching evidenced based review databases such as the Cochrane Library Database of systematic reviews (regarding health care interventions) and the Research Findings electronic Register (ReFeR) Database (findings of research studies funded by the Department of Health).
- Ovid Online containing full text electronic journals and electronic book collections.
- ProQuest which is a service that provides full text journals from medicine, nursing and allied health, psychology and health management fields.
- Zetoc which enables access to the British Library Electronic Table of Contents database of over 20,000 journals.

Specialist databases were also searched, such as the Social Care Institute for Excellence (SCIE) the British Institute for Learning Disabilities (BILD) via their CAS online facility.

Electronic searches were categorised to tackle the multi-faceted evidence base for the project. As an initial step in the process, broad concepts were identified as a platform from which to base the literature review. The search facility on each database is subtly (or significantly) different from another though in most cases the included the search terms below:

- learning disability
- access to healthcare
- service user involvement
- staff awareness of disability
- secondary or acute care
- communication
- awareness.

Where possible the searches were first carried out to cover the widest areas possible, for example by:

- using “search all” facilities where possible to check the abstract, title and body of the text for keywords
- exploding terms (for example in Dialog, the term learning disability can be exploded to cover
- using wildcards (truncation symbols, such as * or $ to expand the scope of the search e.g. access* to encompass access, accessing, accessed, accessibility).
- using search term standardising facilities (such as MeSH in Ovid to include alternative terms used by authors, for example learning disability is sometimes referred to as learning difficulty, or intellectual disability).

In the cases where the searches generated unmanageable volumes of “hits”, they were then restricted using a variety of techniques, including:

- specifying relationships between words (for example using AND to specify “learning disability” rather than articles covering either “learning” OR “disability”)

- using date and origin parameters (such as searching only articles that have been written in the UK since the introduction of the Valuing People publication in 2001).

In cases where a particular article was of interest and relevance, a "snowball search" (George Washington University 2007) of that paper's reference list was conducted to reveal other potentially useful studies and / or names of authors whom could be searched for associated work.

Searches using generic web search engines were also conducted. This helped to gain a general overview of the subject areas by highlighting key organisations involved in similar work (for example MENCAP) and also revealed associated / parallel topics, such as access issues facing patients with mental health disorders rather than specifically learning disabilities. Another function of search engines that proved beneficial was the availability of some (not all) literature / articles that have been uploaded to view. For example, some references (in particular the Nominal Group Technique search stream) for this project were pursued through the Google Scholar facility.

In addition, many of the guides to producing projects at doctoral level (such as Thomas 2000 and Murray 2006) urge students to make use of specialist librarian services in order to access the most up to date data searching tools and ensure that no stones are left unturned in the literature search. A consultation with an NHS Liaison Librarian suggested that setting up an RSS feed would enhance the quality and freshness of the knowledge informing this project. The BBC (2008: webpage) website explains:

> *"Using RSS (Really Simple Syndication) allows you to see when sites from all over the internet have added new content….without having to remember to visit each site every day. RSS takes the hassle out of staying up-to-date, by showing you the very latest information that you are interested in. RSS feeds are just a special kind of web page, designed to be read by computers rather than people".*

In particular, RSS can reveal associated information that may not otherwise be located by formal searches of the evidence. Examples of sites that generated potentially useful information using RSS included the Healthcare Commission, the National Institute for Clinical Excellence, the Department of Health and the King's Fund. These were accessed through an "E-News" facility (rather than setting up individual RSS feeds) operated by the in-house library, which offered a weekly round up of news regarding health services and policy.

The NHS Liaison Librarian also advised conducting a search of dissertations and theses on related subjects. However, this revealed little of significance other than to providing more focused references lists from which to conduct a "snowball search".

Networking was considered an important element of widening the scope of the search for information and evidence. There were wide-ranging reasons for making email, telephone or face to face (at conferences and meetings) contact with local and national key figures and organisations in the field of learning disability. Firstly it was opportunity to enquire whether potential (and interest) existed regarding the sharing of information and ideas for practice based on the work of the project group and to raise the profile of this work. It was also asked whether there may be any work in progress (not yet published) that might be of interest or value to the project. An example of this was being informed of the consultation project underway by the Independent Inquiry into Access into Healthcare for People with Learning Disabilities (2007). Contacts were often able to recommend establishing links with other individuals working in associated / relevant areas, similar to the "snowball" technique for sampling participants (Trochim 2002). Finally, in some circumstances, the experts was asked to nominate a paper, book or project that that has proved invaluable for informing practice and progress that might in turn prove useful to this project; this was based on a suggestion by Thomas (2000).

Some time was dedicated at the beginning of the project to refreshing knowledge about the optimal way to critically appraise literature. The following

sources were used to revise and refresh methods for critically appraising the literature:

- Thomas (1997)
- Greenhalgh (2000)
- JAMA's Evidence-Based Medicine Working Group series of users' guides to the medical literature (in particular I (1993), VI (1994), VIII A and B (1995), X (1996), XII (1997) and XX (2000))
- the "webtorial" entitled Preparing Scholarly Reviews of the Literature (George Washington University 2007)
- The Research and Development in Professional Practice Level 4 module (IPH 4015) of the programme, which aimed to facilitate students to "make judgements on the quality and fitness for purpose of research" (Work Based Learning And Accreditation Unit, 2006); reflecting on this was very useful.

The actual management of the supporting literature of the project was handled using Thomas's (page 51, 2000) suggestions for manual organisation and archiving of literature. Index cards were used in which the Harvard reference of the source was recorded along with an outline of the abstract. For sources that were of particular interest, more detailed notes were made on the reverse of the card, for example regarding a critical appraisal of the study. The cards were filed alphabetically in accordance with Thomas's recommendations which advise against thematic grouping due to the fact that themes can be regularly reviewed throughout the course of a project. A decision was made not to use a reference manager system, which is a tool to help maintain the project's list of references and citations and format them correctly in the chosen style (i.e. Harvard). Instead the reference method selected was the "cite while you write" approach. Whilst this meant that the references had to be meticulously checked, it negated the need to learn about a new data management tool.

Appendix M2 (insert excel spreadsheet in final printed copy)

APPENDIX M3:

COMPONENTS OF ORGANISATIONAL REVIEW

Based on Waggoner et al's (1999) framework, the organisational review was conducted by applying a three-stranded approach:

i) Internal influences

A review of the organisation's internal influences involved looking at policies related to the provision of care for people with learning disabilities. There were three strands to this arm of the organisational review; the first two involved electronic searches and the third was based on recommendations. The Computer Services department was consulted about the most effective way to search the electronic policy manual. Firstly a systematic electronic search was carried out of the hospital's 244 policies which involved reading the executive summary of each searching for references to disability or vulnerable people. This was a painstaking procedure that imposed heavily on the project's time-resources and therefore would have been an ideal role for a research assistant. However, funding for such a post was not available to the Project Overview Group. When policies were positively identified (i.e. that they included references to disability or vulnerable people), they were searched for specific objectives and action plans relating to these terms. Secondly, the electronic search facility on was used; terms such as disability and vulnerable were entered to investigate documents to which they related. Thirdly, the Director of Communications and the Trust Secretary, as the individuals who perhaps were the most familiar with the trust's documents, were asked for advice of other documents that might include references to disability.

ii) Transformational issues

Reviewing transformational issues involved looking at the roles and departments responsible for driving forward the learning disability agenda within the organisation. This stage commenced with the identification of the leaders of groups or committees whose roles could pertain to the care of people with disabilities. Part of the evidence presented in a recent NHSLA assessment (NHSLA 2006) included a comprehensive chart outlining the committee

structure and accountability lines of each group. The leads of each group were contacted by email and their terms of reference were requested; these were then analysed for references of disabilities and more specifically, learning disabilities.

iii) Process issues

These were assessed by looking at the mechanisms in place for identifying patients with learning disabilities, such as data collection and recording methods. An examination was conducted of the functionalities of the Patient Administration System (PAS) to find out if the hospital could flag-up any special requirements, such as the need to receive letters in an accessible or alternative or format. Staff, in general, were asked to report how they felt they identified and/or met the needs of patients with learning disabilities. This was done by posting a message on the electronic hospital bulletin board. Looking into the way that the hospital manages admissions and appointment for people with learning disabilities revealed that there was no single department for the coordination. Therefore a decision was taken to focus on succinct areas of care and emails to identify any existing practices were generated to the manager of the Central Booking Service (the “call centre” that plans all outpatient appointments) and the discharge nurses who were responsible for the management of any complex discharges

APPENDIX 3.1:

SAMPLING OF PARTICIPANTS FOR PRELIMINARY NOMINAL GROUP

It was originally intended that the NG would be conducted in the clinical areas identified as being most commonly used by patients with a co-morbidity of learning disabilities. It had been anticipated that the most likely way of doing so would have been to hold groups after nursing handover meetings to ensure high levels of staff availability and low levels of service disruption. However, due to the limitations in the data generated by the hospital about service users, and the services that they had used (already explained in Establishing Baseline Data), it proved more difficult than anticipated to address these specific clinical areas. Therefore, it became apparent that an optimum way of holding an NG would be with a pre-existing group of nursing staff. The Nurse Induction Programme is a week-long training programme for qualified nursing staff new to the organisation or who have moved within the organisation to a new nursing post. It covers essential information as well as mandatory training. A request was submitted to the Nursing Executive to conduct the NG as part of a nursing induction and was approved on the grounds that it would raise awareness of issues facing patients with learning disabilities.

The sampling of participants was purposive rather than being a convenience sample; the decision to use the attendees of the nurse induction was based on the fact that they were experts in their fields (i.e. qualified general nurses). Trochim (2006) recognises expert sampling as a sub-type of non-probabilistic sampling. Rigor in social research can be supported through systematic non-probabilistic sampling as it minimises the possible bias arising from selecting a sample on the basis of convenience:

> "*Informants are identified because they will enable exploration of a particular aspect of behaviour relevant to the research".*
>
> (Mays and Pope, 1995: webpage)

The sample size of 23 participants represented 1.3% of the total number of nurses in the trust (see Rationale for using the Nominal Group below). Attendees on the induction programme ranged from senior nurses (such as

matrons) to newly qualified nurses and therefore were representative of the various levels of nursing staff within the organisation. The requirements for attendance on the induction programme dictated the inclusion criteria (i.e. that participants were qualified nurses who worked, or were going to work, in the hospital) and eliminated the need to stipulate exclusion criteria.

The number of participants is acknowledged as being high for a group exercise. Whilst Van de Ven and Delbeq (1974) suggest that optimal group size for NGs should be between five and nine members, Thomas (1983) argues that practical reasons can dictate that the group may need to be bigger (she carried out NGs with upwards of 15 participants at a time). Conducting the NG as a session on the nurse induction session ensured good attendance from participants meeting the inclusion criteria as well as representation of the wider population of nurses in the trust. The practical benefits, therefore, were felt to outweigh the potential disadvantages of having a large number of participants.

M4a – Participant information sheet (sent to participants before NG1)

Nominal Group Exercise

Nurse Induction Programme

"What challenges do we currently face when working with people with learning disabilities?"

This information is for nurses who will be attending the nurse induction programme in January 2008. The programme will include a session about working with people with learning disabilities. You are being invited to take part, but it is important that you first find out what will happen and why.

Background

St George's has worked hard over the last few years to improve the accessibility of its site and services for patients and their relatives. Initiatives have included improvements to:

- Staff training and awareness
- Patient information
- Site and facilities.

A lot of this work has focused on looking at the needs of people with learning disabilities; as we have said many times "if you get things right for people with learning disabilities, you get things right for a lot of people".

Current situation

The learning disability project work has recently increased its scope and pace, and is multi-faceted. We are enjoying enthusiastic and effective working relationships with key learning disability staff from the community.

We need to find out if the projects that we **think** are going to work **will** actually work. One way to do this is to see if it has made a difference to staff; their awareness and experiences. Therefore, before we start implementing any of the work, we want to find out what staff think now. After a period of time (about

six months), when the project work is underway, we plan to ask nurses again to see if it has made a difference.

Another way of finding out if the projects are effective is to ask service users with learning disabilities what they think. We are also doing this.

What will we be doing in the session on the nurse induction programme?
We will be trying to find out "What challenges do we currently face when working with people with learning disabilities?" by using the **nominal group technique**.

We are doing this in the nurse induction programme because we hope will provide us with a views and outcomes that represent nursing staff, from all levels in the organisation.

What is the nominal group technique?
One definition is "a structured meeting [to] obtain qualitative information from target groups who are most closely associated with a problem area" (Fink et al 1984).

It is a 'consensus method', which basically means that judgments can be pooled (put together) to identify a problem and find a solution(s). Consensus methods are becoming more popular as they don't involve questionnaires, audits or interviews and are quick to carry out. This will take about 60 minutes of the meeting today.

What about confidential information?
Your name will not be recorded during the session. You will be asked to complete an attendance form with your designation (band), your age (in age groups) and the number of years since you qualified as a nurse.

The only notes taken will be ideas written on a flip chart. This will be kept by the facilitator (Kirsty Glaysher) until a report has been written.

What will happen with the information discussed?

The findings of the group will be used to form recommendations. These will be used by St George's to help wards and departments improve access for people with learning disabilities. You will not be named in the report at all.

What are the advantages and disadvantages of coming to a group?

The benefits to you are the opportunity to share ideas about improving access for people with learning disabilities and refresh / learn new knowledge about communicating with people with learning disabilities. The disadvantages are that you will need to give your time.

Any questions?

The exercise will be fully explained first and you will have the opportunity to ask questions. If you have any questions or concerns before the meeting, please email kirsty.glaysher@stgeorges.nhs.uk or call 020 8266 6128.

M4b – Participant information sheet (sent to participants at the start of NGT1)

Plan for Nominal Group Exercise

Nurse Induction Programme

"What challenges do we currently face when working with people with learning disabilities?"

What are we doing today?

We will be trying to find out "What challenges do we currently face when working with people with learning disabilities?" by using the **nominal group technique**.

We are doing this in the nurse induction programme because we hope will provide us with a views and outcomes that represent nursing staff, from all levels in the organisation.

What is the nominal group technique?

One definition is "a structured meeting [to] obtain qualitative information from target groups who are most closely associated with a problem area" (Fink et al 1984).

It is a 'consensus method', which basically means that judgments can be pooled to identify a problem and find a solution(s). Consensus methods are becoming more popular as they don't involve questionnaires, audits or interviews and are quick to carry out. This will take about 60 minutes of the meeting today.

Any questions before we start?

What happens next?

1. Ground rules

- You are free to leave now or at any point during the exercise.
- There are no right or wrong answers.
- This is a consensus method so we want to consolidate (bring together) a range of opinions – you do not need to conform with others!
- The views of individuals should remain anonymous (the outcome of the exercise will be written in the minutes and can be shared).

2. We will read a case study about a patient with learning disabilities, from the Mencap report "Death by Indifference" (2007).

3. We will watch a short video produced by people with learning disabilities, entitled "Let's be patient". It shows the patient's journey from receiving a letter from the hospital, to attending an appointment at hospital. It was produced as an aid to help prepare patients with learning disabilities for admissions to hospital but was also intended to be used as a training tool for staff to see things from a patient's experience.

4. We will spend 5 minutes writing down our views on the question

   "What challenges do we currently face when working with people with learning disabilities?"

   Try to think about your own area of work or involvement as a starting point. Try also to think as broadly as you can – considering previous experiences and potential ideas. Think about the whole patient journey….

5. We will write down all the ideas on the flip chart by going around the room and each mentioning one. We will then go around the table again and repeat this until we have exhausted our lists.

6. We will then vote on each idea to say whether we think they are important or not. The scoring system is 3 = most important and 1 = least important. Average scores are calculated for each idea and we will get rid of those with the lowest score.

7. Does anyone have any new ideas at this stage? If so, we will repeat steps 5 to 6.

8. We can write down our opinions of the results on a feedback sheet. The sheet also has the following questions for you to think about:
    - Do you think the exercise reflected the general opinions of the groups?
    - Did you agree with the final ranking?
    - Were there any ideas that you were sorry to see go due to their score being too low?

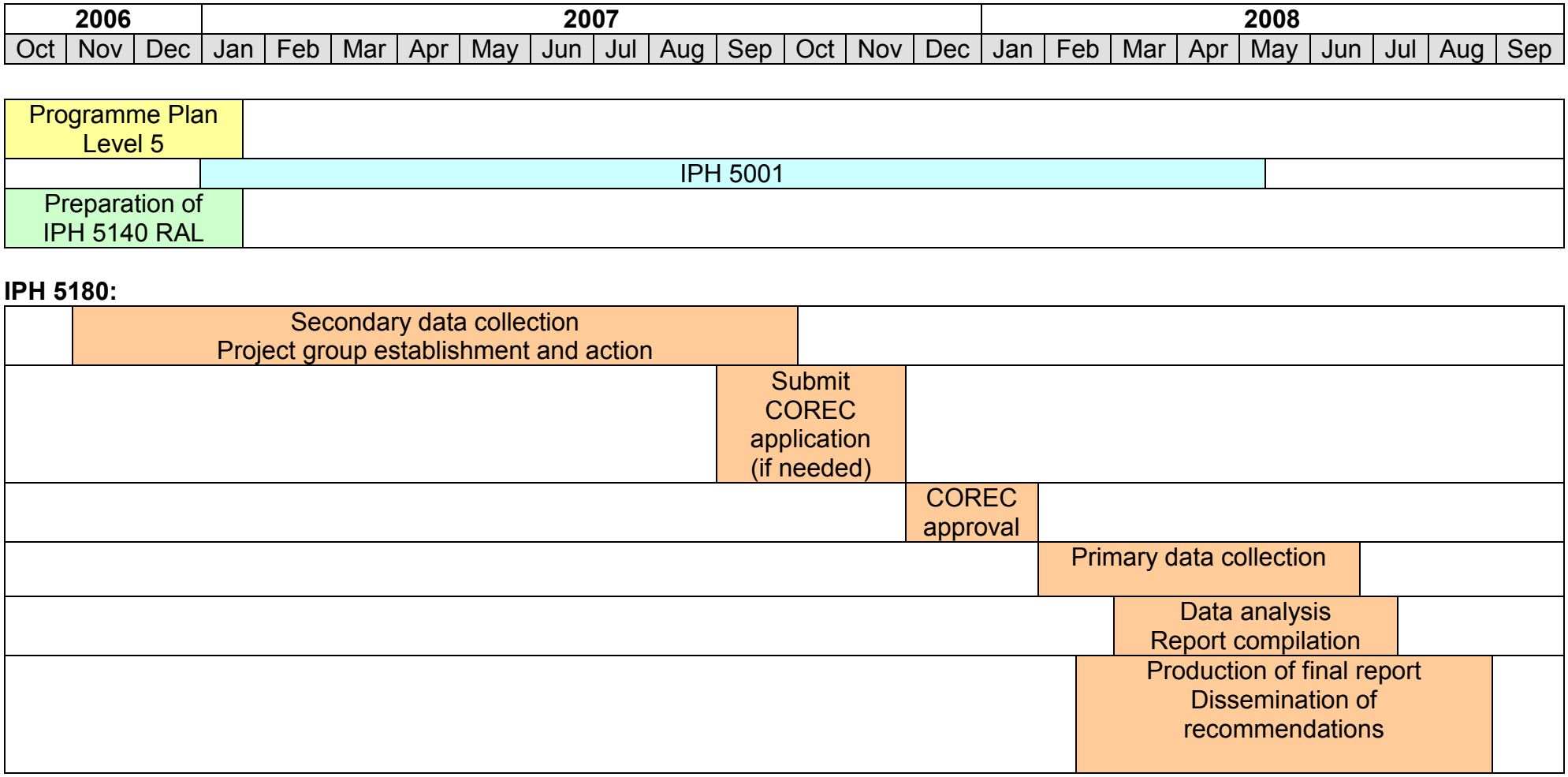
Any questions?

What happens now?

A summary of the group and a report about the results will be available. If you have any questions or concerns about the meeting, please email kirsty.glaysher@stgeorges.nhs.uk

APPENDIX M5

PROGRAMME TIME PROFILE



Insert M6 – scanned copy of passport – first page (blank page inserted here so page numbers in final bound copy are correct)

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Insert M6 – scanned copy of passport – seventh page (blank page inserted here so page numbers in final bound copy are correct)

APPENDIX M6.1

SAMPLING OF PARTICIPANTS FOR FOLLOW-UP NOMINAL GROUP

The second NGT was not held as part of the Nursing Induction Programme again as it needed to be sensitive to any changes in perceived awareness levels of staff; a new intake of Induction Programme attendees, who would predominantly be new to the organisation, would not have been exposed to the Hospital Passports. The second NG was held in a Sisters' Meeting attended by sisters/charge nurses from various settings within the hospital. A session was booked on the agenda of the bimonthly meeting six months after the first hospital passport had been used and after 20 patients had used passports during an admission. Participant information (see Appendix M7) was distributed before the meeting by the administrative coordinator, along with the agenda for the meeting and accompanying paperwork. A covering email sent with the paperwork explained that the Sisters' Meeting would be split into two sessions; the Nominal Group for senior staff who had experienced the use of the hospital passports (or whose teams had) and a second group for staff who had not encountered the passports. This group covered another topic (a review of the treatment of prisoners at the hospital), which the attendees of the follow-up nominal group were provided with an alterative opportunity to attend.

The justification for this sample of participants was that similarities existed with the first group; they were qualified nurses working in the same hospital. It was felt that the Sisters could readily report on the impact of the passports on behalf of their teams and therefore that they could represent the wider population of nurses across the organisation. The role of the Sister is a synthesis of clinical and managerial duties as it operates at the interface of frontline care provision and strategic management (Casteldine 2001). As in the previous NG, the method of sampling was purposive; the criteria for inclusion was that the nurses worked at the grade of Sister/Charge Nurse or above, within the hospital.

M7a – Participant information sheet (sent to participants before NGT2)

Nominal Group Exercise

Sisters' Meeting

"How have hospital passports improved your awareness of the needs of people with learning disabilities?"

This information is for nurses who will be attending the Sister's Meeting in June 2008. We are hosting a session especially for nurses who have worked with learning disabled patients using hospital passports. You are being invited to take part, but it is important that you first find out what will happen and why.

Background

St George's has worked hard over the last few years to improve the accessibility of its site and services for patients and their relatives. Initiatives have included improvements to:

- Staff training and awareness
- Patient information
- Site and facilities

A lot of this work has focused on looking at the needs of people with learning disabilities; as we have said many times "if you get things right for people with learning disabilities, you get things right for a lot of people".

Current situation

The learning disability project work has recently increased its scope and pace, and is multi-faceted. We are enjoying enthusiastic and effective working relationships with key learning disability staff from the community.

We need to find out if our plans and projects are making a difference, to service users, carers and staff. One way to do this is find out about staff awareness and

experiences. Six months ago, we asked nurses on the trust induction programme what they considered to be the major challenges when working with people with learning disabilities. Since then, the project work has been underway:

- we have started using the hospital passport
- information has been distributed about how to contact the community learning disability teams for specialist support
- we have a regular slot on the nurse induction programme about working with patients with communication difficulties.

Another way of finding out if the projects are effective is to ask service users with learning disabilities what they think. We are also doing this.

What will we be doing in the session at the Sister's Meeting?

We will be trying to find out "How have hospital passports improved your awareness of the needs of people with learning disabilities?" by using the **nominal group technique**.

We are doing this in the nurse induction programme because we hope will provide us with a views and outcomes that represent nursing staff, from all levels in the organisation.

What is the nominal group technique?

One definition is "a structured meeting [to] obtain qualitative information from target groups who are most closely associated with a problem area" (Fink et al 1984).

It is a 'consensus method', which basically means that judgments can be pooled (put together) to identify a problem and find a solution(s). Consensus methods are becoming more popular as they don't involve questionnaires, audits or interviews and are quick to carry out. This will take about 60 to 90 minutes of the meeting today.

What about confidential information?

Your name will not be recorded during the session. You will be asked to complete an attendance form with your designation (band), your age (in age groups) and the number of years since you qualified as a nurse.

The only notes taken will be ideas written on a flip chart. This will be kept by the facilitator (Kirsty Glaysher) until a report has been written.

What will happen with the information discussed?

The findings of the group will be used to form recommendations. These will be used by St George's to help wards and departments improve access for people with learning disabilities. You will not be named in the report at all.

What are the advantages and disadvantages of coming to a group?

The benefits to you are the opportunity to share ideas about improving access for people with learning disabilities and refresh / learn new knowledge about communicating with people with learning disabilities. The disadvantages are that you will need to give your time.

Any questions?

The exercise will be fully explained first and you will have the opportunity to ask questions. If you have any questions or concerns before the meeting, please email kirsty.glaysher@stgeorges.nhs.uk or call 020 8266 6128.

M7b – Participant information sheet (sent to participants at the start of NGT2)

Nominal Group Exercise

Sisters' Meeting June 2008

"How have hospital passports improved your awareness of the needs of people with learning disabilities?"

Background

St George's has worked hard over the last few years to improve the accessibility of its site and services for patients and their relatives. Initiatives have included improvements to:

- Staff training and awareness
- Patient information
- Site and facilities

A lot of this work has focused on looking at the needs of people with learning disabilities; as we have said many times "if you get things right for people with learning disabilities, you get things right for a lot of people".

Current situation

The learning disability project work has recently increased its scope and pace, and is multi-faceted. We are enjoying enthusiastic and effective working relationships with key learning disability staff from the community.

We need to find out if our plans and projects are making a difference, to service users, carers and staff. One way to do this is find out about staff awareness and experiences. Six months ago, we asked nurses on the trust induction programme what they considered to be the major challenges when working with people with learning disabilities. Since then, the project work has been underway:

- we have started using the hospital passport

- information has been distributed about how to contact the community learning disability teams for specialist support
- we have a regular slot on the nurse induction programme about working with patients with communication difficulties.

Another way of finding out if the projects are effective is to ask service users with learning disabilities what they think. We are also doing this.

What are we doing today?

We will be trying to find out "How have hospital passports improved your awareness of the needs of people with learning disabilities?" by using the **nominal group technique**.

We are doing this in the sisters' meeting because we hope will provide us with a views and outcomes that represent nursing staff, both generally and from a strategic point of view.

What is the nominal group technique?

One definition is "a structured meeting [to] obtain qualitative information from target groups who are most closely associated with a problem area" (Fink et al 1984).

It is a 'consensus method', which basically means that judgments can be pooled (put together) to identify a problem and find a solution(s). Consensus methods are becoming more popular as they don't involve questionnaires, audits or interviews and are quick to carry out. This will take about 60-90 minutes of the meeting today.

Any questions before we start?

What happens next?

1. Ground rules
    - You are free to leave now or at any point during the exercise.

- There are no right or wrong answers.
- This is a consensus method so we want to consolidate a range of opinions – you do not need to conform with others!
- The views of individuals should remain anonymous (the outcome of the exercise will be written in the minutes and can be shared).

2. We will read a case study about a patient with learning disabilities, from the Mencap report “Death by Indifference” (2007).

3. We will spend 5 minutes writing down our views on the question

   “How have hospital passports improved your awareness of the needs of people with learning disabilities?”

   Try to think about your own area of work or involvement as a starting point. Try also to think as broadly as you can – considering previous experiences and potential ideas. Think about the whole patient journey….

4. We will write down all the ideas on the flip chart by going around the room and each mentioning one and clarifying / grouping if necessary. We will then go around the table again and repeat this until we have exhausted our lists.

5. We will then each get to vote on the three most important ideas. The scoring system is 3 = most important and 1 = least important. As time will probably be limited, we will probably mark these ourselves on the flip charts.

6. Does anyone have any new ideas at this stage? If so, we will repeat step 5 and 6.

7. We can write down our opinions of the group and ideas on a feedback sheet. The sheet is for you to write any comments you might have – consider the following questions:
   - Do you think the exercise reflected the general opinions of the groups?
   - Did you agree with the final ranking?
   - Is there anything else you wanted to add?

Any questions?

What happens now?

If you have any questions or concerns about the group please email kirsty.glaysher@stgeorges.nhs.uk or call 020 8266 6128. A summary report of the group's findings will be circulated with the agenda for your next meeting.

M8 Experience of hospital passport: evaluation form

Evaluation questions for pilot of the Hospital Passport

Use these questions to form the basis of the interview with the patient (and/or their carer if appropriate). If the patient is able, they can complete this form themselves. The questions can be reworded if needed or conveyed using alternative communication.

1. Where were you/the person admitted to hospital from?

2. Was the passport used as soon as you/the person went into hospital?

3. How was the passport used in the clinical setting?

4. Did the passport make a difference to the plan of care and treatment provided?

5. Was the passport helpful?

6. If it was how and why was it helpful?

7. What things would you like to change or think should be added onto the passport?

8. Any other comments?

APPENDIX M9:
ETHICAL ISSUES

The following information aims to comprehensively identify and explain the ethical issues that were addressed in order to ensure the integrity of the project.

Professional codes of conduct

It is important to acknowledge the essential role played by codes of conduct and professional guidelines in the ethical debate surrounding a work based learning project in health. The author's professional background is in Occupational Therapy (OT) and the British Association of OTs has well formed guidance regarding professional practice available to its members (Mandalstam 2005). The author was not practicing as a clinician for the duration of the project or production of the report and therefore was not state registered as an Occupational Therapist. Nevertheless the professional code of practice is somewhat inextricably embedded in personal conduct from over twelve years in OT practice. In addition to any professional accountability, Bell (2005, page 58) points out that research should be "conducted in a way that conforms to [one's] own ethical principles".

Ethical approval

The project needs to adhere to the standards in the national health research strategy (DOH 2006) which meant that ethical approval needed to be gained (or waived) before any primary data collection could take place. As this project formed part of a Doctorate in Professional Studies (DProf) in Health, Middlesex University was the identified sponsoring organisation, accepting duties to oversee the quality issues of the research elements of the project.

An application in the form of a letter accompanied by a detailed research protocol was submitted to the Local Ethics Research Committee (LREC) in line with the requirements of the Central Office for Research Ethics Committee (COREC). A letter (see Appendix M10) was received from the LREC chair confirming that the project would be considered as a "service evaluation" as opposed to "research" and therefore did not require review by an NHS Research Ethics Committee or approval from the NHS Research and Development Office. I also telephoned the LREC office

and spoke to the coordinator to confirm my understanding of the letter. Reflections of the decision of the LREC and its implications are outlined in 5.3.4.

Data handling

For the duration of the research and production of the report, the NGT paperwork (such as the flip chart pages, and participant notes / comments sheets) was stored securely. There was no possibility of identification of participants as names were not recorded. All data will be destroyed after completion of the final report and viva voce. The participant information states that the data would not be used for any other purpose.

Data associated with the elements of the project lead by the Learning Disability Nurse Manager (such as the forms used in the patient interviews) was recorded and stored in the locality office of the Nurse Manager.

The data generated by the Information Development Team was also anonymous. It was specifically requested that it was not identifiable by patient details (name, date of birth or hospital number). This avoided having to tackle any complex issues regarding the holding of, and sending by, information by computer as outlined in the Caldicott Report (DOH 1997).

Issues of the 'Insider Researcher'

In addition to the other ethical issues covered in this section, qualitative research can also generates specific ethical problems due to the close relationship that researchers form with participants. In work based learning, this can be further accentuated by concept of the" insider researcher" (Frazer 1997); the possibility that the researcher could influence (consciously or unconsciously), initiate and / or achieve significant innovations in practice or service delivery due to the fact that they are embedded within their organisation. However, in a very comprehensive overview of this issue, Bell (2005) identifies that there are considerable advantages of insider research. These include having an intimate knowledge of the content of the research, being aware of the "micropolitics of the institution" (page 53), being able to access subjects, being able to understand some of the issues or difficulties of working in the organisation and being identifiable to the participants as a colleague and therefore

someone to whom they welcome the opportunity to air their views. Conversely, the limitations of having an insider researcher also need to be acknowledged; Bell goes on to explain that the disadvantages include a possible feeling of awkwardness when conducting research with colleagues, the fact that you might have to "live with your mistakes after completing your research" (page 53) and a difficulty in maintaining objectivity. It can be concluded, though, that despite the potential disadvantages, insider research enables us to ground our research in everyday issues:

> *"[Insider research is] worthwhile and special because it helps solve practical problems ….. that cannot be tackled as effectively by more traditional forms of research".*
>
> (Smyth and Holian, 1999 in Tenni et al, 2003: webpage)

Ethical Issues associated with the NGs

Both Nominal Groups commenced with agreement of ground rules which explained the anonymity of participants and the fact that the views of individuals should remain anonymous outside of the groups. It was explained to participants (both on in the information sheets and during the groups themselves) that a report covering the group findings and how they would be used would be available to them, which would allow participants to discuss the content and outcome of the groups without revealing ownership of opinions. Participants' names were not collated; therefore if participants wanted a copy of the report, they would need to contact the facilitator and her contact details were provided.

In order to ensure that participants were able to give make an informed decision about participation, they were sent information (see Appendices M4 and M7) by email attachment prior to the group which explained the purpose of the group, what the NGT is, what the NG would involve and how the findings would be used. It also advised that participation in the NGT was voluntary and that participation could be withdrawn at any time. As anonymity was protected, the participant information was circulated by an administrator within the Nursing Directorate (who coordinates both the Sisters' Meetings and the Nurse Induction) without the facilitator knowing who was on the circulation lists. As each group commenced, a further information sheet was read through with the group to ensure that all participants fully understood. The

issue of consent is a complex and intricate one and guidance was sought from the literature as well as professional best practice guidelines (such as RCN 2005). The participants' consent for involvement was not formally recorded as their attendance at the Nominal Groups, and agreement to remain in the group, was considered as implied consent.

The possible advantages of participation included the opportunity to be involved in service planning and policy development (Cass 2006). In fact the NHS "Improving Working Lives" (DOH 2000a) document focuses on the development and retention of a qualified capable workforce and acknowledges the importance of opportunities for involvement in service improvements. The potential adverse effects include the participants giving up their time and discussing a potentially emotive issue, such as having had negative experiences of working with patients with learning disabilities. The contact details of the facilitator (author) were provided to all participants in the event that anyone had any later concerns or questions about the group, their involvement.

Involving Service Users with Learning Disabilities

When planning a project that claims to be inclusive, the involvement of service users is imperative; serious ethical issues relate to projects not involving consumers (Beresford 2005). Inclusivity is defined as being when a participant "feels able to contribute as fully and equally as they would wish" Steel (2005, page 20). Since the profile and importance of patient and public involvement (PPI) was raised around 2003/4 (see the Introduction) involving consumers has become increasingly important in health care research and service improvement. However, it is also critical not to pay lip service to this or subscribe to tokenism as these will result in poor practice in this area.

The planning stage of any project involves ethical decisions weighing up benefit versus potential harm. In this case, as has already been noted, the author took the decision not to work directly with service users with learning disabilities. Entrusting the involvement element of the project to the learning disabilities nurses entailed acknowledging the specialist skills and experience possessed by colleagues. It was within their existing professional remit to have contact with, communicate with,

support and promote access to services for their clients with learning disabilities and their carers. Issues surrounding service user involvement for people with learning disabilities mainly relate to the capacity to understand the pros and cons of involvement work, making informed decisions/consent and communicating experiences/concerns. Due to their experience and professional practice requirements, the learning disability nurses were ideally placed to assess their clients' abilities in these areas relating the completion of hospital passports and the evaluation interviews.

M10 – insert scanned copy of letter from ethics committee – first page

M10 – insert scanned copy of letter from ethics committee – second page

APPENDIX R1.1

EXTRACTS FROM INFORMATION DEPARTMENT'S DATABASE OF DIAGNOSES: CODES RELATED TO LEARNING DISABILITY

F70.0	Mild mental retardation	Mld mental retard with statement no or min impairm behave
F70.1	Mild mental retardation	Mld mental retard sig impairment behave req attent /treat
F70.8	Mild mental retardation	Mild mental retardation, other impairments of behaviour
F70.9	Mild mental retardation	Mild mental retardation without mention of impairment behav
F71.0	Moderate mental retardation	Mod mental retard with statement no or min impairm behav
F71.1	Moderate mental retardation	Mod mental retard sig impairm of behave req attent /treat
F71.8	Moderate mental retardation	Moderate mental retardation, other impairments of behaviour
F71.9	Moderate mental retardation	Mod mental retard without mention of impairment of behav
F72.0	Severe mental retardation	Sev mental retard with statement no or min impairm behav
F72.1	Severe mental retardation	Sev mental retard sign impairm behav req attent /treatment
F72.8	Severe mental retardation	Severe mental retardation, other impairments of behaviour
F72.9	Severe mental retardation	Severe mental retard without mention of impairment of behav
F73.0	Profound mental retardation	Prof mental retard with statement no or min impairm behav
F73.1	Profound mental retardation	Prof mental retard sig impairm behav req attent/treatment
F73.8	Profound mental retardation	Profound mental retardation, other impairments of behaviour
F73.9	Profound mental retardation	Profound mental retard without mention of impairm behav
F78.0	Other mental retardation	Oth mental retard with statment of no or min impairm behav
F78.1	Other mental retardation	Oth mental retard sig impairm of behave req attent / treat
F78.8	Other mental retardation	Other mental retardation, other impairments of behaviour
F78.9	Other mental retardation	Other mental retardation with other impairments of behaviour
F79.0	Unspecified mental retardation	Unspec mental retard with statement no or min impair behav
F79.1	Unspecified mental retardation	Unspec mental retard sign impairm behave requir attent/treat
F79.8	Unspecified mental retardation	Unspec mental retardation
F79.9	Unspecified mental retardation	Unspec mental retard without mention of impairment of behav
F81.0	Specific developmental disorders of scholastic skills	Specific reading disorder
F81.1	Specific developmental disorders of scholastic skills	Specific spelling disorder
F81.2	Specific developmental disorders of scholastic skills	Specific disorder of arithmetical skills

F81.3	Specific developmental disorders of scholastic skills	Mixed disorder of scholastic skills
F81.8	Specific developmental disorders of scholastic skills	Other developmental disorders of scholastic skills
F81.9	Specific developmental disorders of scholastic skills	Developmental disorder of scholastic skills, unspecified

Q90.0	Down's syndrome	Trisomy 21, meiotic nondisjunction
Q90.1	Down's syndrome	Trisomy 21, mosaicism (mitotic nondisjunction)
Q90.2	Down's syndrome	Trisomy 21, translocation
Q90.9	Down's syndrome	Down's syndrome, unspecified
Q91.0	Edwards' syndrome and Patau's syndrome	Trisomy 18, meiotic nondisjunction
Q91.1	Edwards' syndrome and Patau's syndrome	Trisomy 18, mosaicism (mitotic nondisjunction)
Q91.2	Edwards' syndrome and Patau's syndrome	Trisomy 18, translocation
Q91.3	Edwards' syndrome and Patau's syndrome	Edwards' syndrome, unspecified
Q91.4	Edwards' syndrome and Patau's syndrome	Trisomy 13, meiotic nondisjunction
Q91.5	Edwards' syndrome and Patau's syndrome	Trisomy 13, mosaicism (mitotic nondisjunction)
Q91.6	Edwards' syndrome and Patau's syndrome	Trisomy 13, translocation
Q91.7	Edwards' syndrome and Patau's syndrome	Patau's syndrome, unspecified
Q92.0	Other trisomies and partial trisomies of the autosomes NEC	Whole chromosome trisomy, meiotic nondisjunction
Q92.1	Other trisomies and partial trisomies of the autosomes NEC	Whole chromosome trisomy, mosaicism (mitotic nondisjunction)
Q92.2	Other trisomies and partial trisomies of the autosomes NEC	Major partial trisomy
Q92.3	Other trisomies and partial trisomies of the autosomes NEC	Minor partial trisomy
Q92.4	Other trisomies and partial trisomies of the autosomes NEC	Duplications seen only at prometaphase
Q92.5	Other trisomies and partial trisomies of the autosomes NEC	Duplications with other complex rearrangements
Q92.6	Other trisomies and partial trisomies of the autosomes NEC	Extra marker chromosomes
Q92.7	Other trisomies and partial trisomies of the autosomes NEC	Triploidy and polyploidy
Q92.8	Other trisomies and partial trisomies of the autosomes NEC	Other specified trisomies and partial trisomies of autosomes
Q92.9	Other trisomies and partial trisomies of the autosomes NEC	Trisomy and partial trisomy of autosomes, unspecified
Q93.0	Monosomies and deletions from the autosomes NEC	Whole chromosome monosomy, meiotic nondisjunction
Q93.1	Monosomies and deletions from the autosomes NEC	Whole chrom monosomy mosaicism (mitotic nondisjunction)
Q93.2	Monosomies and deletions from the autosomes NEC	Chromosome replaced with ring or dicentric
Q93.3	Monosomies and deletions from the autosomes NEC	Deletion of short arm of chromosome 4

Q93.4	Monosomies and deletions from the autosomes NEC	Deletion of short arm of chromosome 5
Q93.5	Monosomies and deletions from the autosomes NEC	Other deletions of part of a chromosome
Q93.6	Monosomies and deletions from the autosomes NEC	Deletions seen only at prometaphase
Q93.7	Monosomies and deletions from the autosomes NEC	Deletions with other complex rearrangements
Q93.8	Monosomies and deletions from the autosomes NEC	Other deletions from the autosomes
Q93.9	Monosomies and deletions from the autosomes NEC	Deletion from autosomes, unspecified
Q95.0	Balanced rearrangements and structural markers NEC	Balanced translocation and insertion in normal individual
Q95.1	Balanced rearrangements and structural markers NEC	Chromosome inversion in normal individual
Q95.2	Balanced rearrangements and structural markers NEC	Balanced autosomal rearrangement in abnormal individual
Q95.3	Balanced rearrangements and structural markers NEC	Balanced sex/autosomal rearrangement in abnormal individual
Q95.4	Balanced rearrangements and structural markers NEC	Individuals with marker heterochromatin
Q95.5	Balanced rearrangements and structural markers NEC	Individuals with autosomal fragile site
Q95.8	Balanced rearrangements and structural markers NEC	Other balanced rearrangements and structural markers
Q95.9	Balanced rearrangements and structural markers NEC	Balanced rearrangement and structural marker, unspecified
Q96.0	Turner's syndrome	Karyotype 45,X
Q96.1	Turner's syndrome	Karyotype 46,X iso (Xq)
Q96.2	Turner's syndrome	Karyotype 46,X with abnormal sex chromosome, except iso (Xq)
Q96.3	Turner's syndrome	Mosaicism, 45,X/46,XX or XY
Q96.4	Turner's syndrome	Mosaicism 45X/oth cell line(s) with abnorm sex chromosome
Q96.8	Turner's syndrome	Other variants of Turner's syndrome
Q96.9	Turner's syndrome	Turner's syndrome, unspecified
Q97.0	Other sex chromosome abnormalities, female phenotype NEC	Karyotype 47,XXX
Q97.1	Other sex chromosome abnormalities, female phenotype NEC	Female with more than three X chromosomes
Q97.2	Other sex chromosome abnormalities, female phenotype NEC	Mosaicism, lines with various numbers of X chromosomes
Q97.3	Other sex chromosome abnormalities, female phenotype NEC	Female with 46,XY karyotype
Q97.8	Other sex chromosome abnormalities, female phenotype NEC	Oth spec sex chromosome abnormalities female phrenotype
Q97.9	Other sex chromosome abnormalities, female phenotype NEC	Sex chromosome abnormality, female phenotype, unspecified
Q98.0	Other sex chromosome abnormalities, male phenotype NEC	Klinefelter's syndrome karyotype 47,XXY
Q98.1	Other sex chromosome abnormalities, male phenotype NEC	Klinefelter's syn male with more than two X chromosomes
Q98.2	Other sex chromosome abnormalities, male phenotype NEC	Klinefelter's syndrome, male with 46,XX karyotype
Q98.3	Other sex chromosome abnormalities, male phenotype NEC	Other male with 46,XX karyotype

Q98.4	Other sex chromosome abnormalities, male phenotype NEC	Klinefelter's syndrome, unspecified
Q98.5	Other sex chromosome abnormalities, male phenotype NEC	Karyotype 47,XYY
Q98.6	Other sex chromosome abnormalities, male phenotype NEC	Male with structurally abnormal sex chromosome
Q98.7	Other sex chromosome abnormalities, male phenotype NEC	Male with sex chromosome mosaicism
Q98.8	Other sex chromosome abnormalities, male phenotype NEC	Other specified sex chromosome abnormalities, male phenotype
Q98.9	Other sex chromosome abnormalities, male phenotype NEC	Sex chromosome abnormality, male phenotype, unspecified
Q99.0	Other chromosome abnormalities, not elsewhere classified	Chimera 46,XX/46,XY
Q99.1	Other chromosome abnormalities, not elsewhere classified	46,XX true hermaphrodite
Q99.2	Other chromosome abnormalities, not elsewhere classified	Fragile X chromosome
Q99.8	Other chromosome abnormalities, not elsewhere classified	Other specified chromosome abnormalities
Q99.9	Other chromosome abnormalities, not elsewhere classified	Chromosomal abnormality, unspecified

Z73.6	Problems related to life-management difficulty	Limitation of activities due to disability
Z73.8	Problems related to life-management difficulty	Other problems related to life-management difficulty
Z73.9	Problems related to life-management difficulty	Problem related to life-management difficulty, unspecified

APPENDIX R1: RESULTS OF REVIEW OF POLICY MANUAL

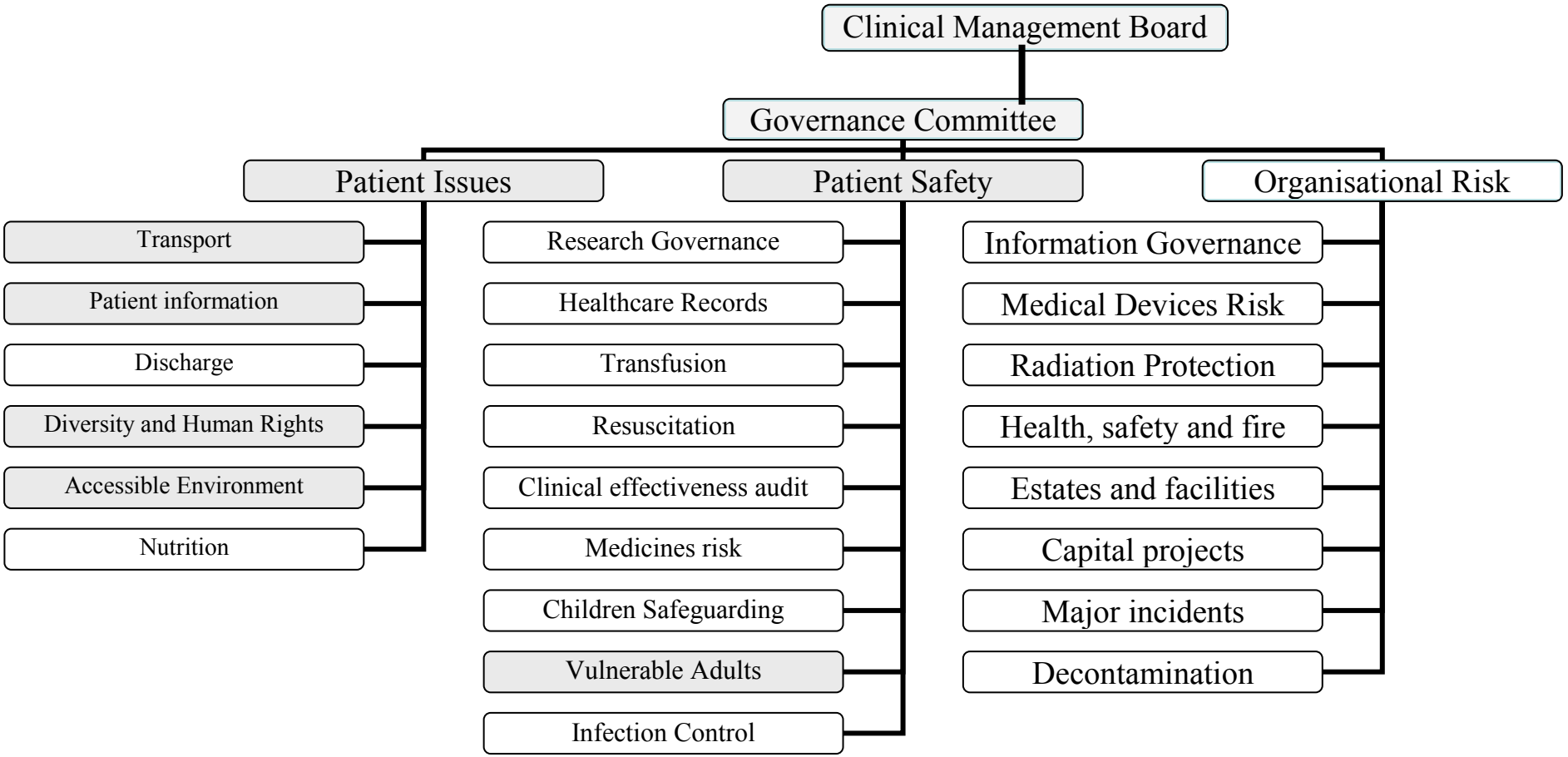
Volume	Section (example of policy in section)	No. of policies in section	Relevant policies (executive summary mentions disability or vulnerable people)	Comments
Clinical	Ethics e.g. Patients Dying in Hospital	4	None	
	Infection control e.g. Hand Hygiene	13	None	
	Medicines e.g. Safe prescribing, handling and administration of cytotoxic drugs	22	None	
	Medical Devices e.g. Atrial defibrillation	8	None	
	Patient Management	59	Safe Discharge of Patients from Hospital	Stipulates action required if abuse of a vulnerable adult is suspected (i.e. that patient cannot be discharged to an unsafe environment).
			Obtaining Valid Consent for Treatment	Outlines requirements for gaining consent for treatment, care or research, including for adults without capacity.

Volume	Section (example of policy in section)	No. of policies in section	Relevant policies (executive summary mentions disability or vulnerable people)	Brief details of policy (discussed in more depth in body of report)
Clinical (cont.)	Patient Management (cont.)		Advance Decisions (Sometimes referred to as Advance Directives or Living wills)	Cross references to policy for obtaining consent regarding establishment of capacity to make decisions.
			Safeguarding Adults	Describes how allegations of abuse of adult patients under the care of the hospital should be managed.
Emergency	e.g. Major Incident	8	None	
Finance	e.g. Fund raising appeals	3	None	
Health and Safety	e.g. Control of substances hazardous to health	27	None	
Information Management /Technology	e.g. Antivirus policy	22	None	

Volume	Section (example of policy in section)	No. of policies in section	Relevant policies (executive summary mentions disability or vulnerable people)	Brief details of policy (discussed in more depth in body of report)
Human Resources	Recruitment and selection	8	The Employment of Disabled People	Stipulates that the Trust will make reasonable changes to premises or employment arrangements for successful candidates who have special needs, if current arrangements substantially disadvantage a disabled employee in comparison to a non-disabled employee. Also states that there is HR Advisor who will act as the designated “Disabilities Officer” for the Trust.
	General employment	29	Equality and Diversity	States “Everyone who works in the Trust, or applies to work in the Trust, should be treated fairly and valued equally. All conditions of service and job requirements should fit with the needs of the service and those who work in it, regardless of age, disability, race, nationality, ethnic or national origin, gender, religion, sexual orientation, domestic circumstances, social and employment status, HIV status, gender reassignment, political affiliation or trade union membership” (St George’s Healthcare NHS Trust 2001).
	Leave	4	None	
	Welfare	12	None	
	Termination of Employment	1	None	

Volume	Section (example of policy in section)	No. of policies in section	Relevant policies (executive summary mentions disability or vulnerable people)	Brief details of policy (discussed in more depth in body of report)
Organisational	Information e.g. Style guidelines	5	Policy for the Production, Approval and Implementation of Corporate Policies	Includes guidance for carrying out an Equality Impact Assessments (needed in all policies) which are a way of thoroughly assessing, and consulting on the effects that a proposed policy is likely to have on people, depending on their racial group, **disability**, age, gender etc
			Patient Information	Provides guidance, including an overview of the legislation, about producing information in alternative formats and languages. Also stipulates considerations for people with learning disabilities, such as producing easy-read / illustrated information.
	Governance	18	Complaints and Concerns Policy and Procedures	Contains guidance (in an appendix) for responding to complaints made by people with learning disabilities (such as tips on how to word the letter).
	Estates and Facilities e.g. Smoke free policy	6	None	
Research	e.g. Intellectual property	3	None	

APPENDIX R2 COMMITTEE STRUCTURE (shaded areas depict committees whose leads were contacted)



APPENDIX R3 TERMS OF REFERENCE FOR COMMITTEES

Group contacted	**Mentioned disability?**	**Mentioned learning disability?**	**Relevant extracts**
Clinical Management Board	No	No	
Governance Committee	No	No	
Patient Safety	Yes	No	To ensure that patient safety procedures are followed for all patients regardless of age, sex, ethnic background, **disability**, culture or sexual orientation.
Vulnerable Adults	Yes	Yes	To ensure that clinical staff receive training appropriate to their roles regarding safeguarding adults, working with people with **learning disabilities** and elder abuse.
Patient Issues	No	No	
Transport	Yes	No	To meet the needs of **disabled** drivers using [the hospital]. To monitor the performance of the Transport Assessment and Booking (TAB) team regarding the use of patient transport services based on medical need and/ or **disability**.
Patient Information	Yes	Yes	To ensure patient information is accessible and appropriate for all services (such as Braille or audio format for people with visual impairments and easy to read or illustrated for people with **learning disabilities**)
Diversity and Human Rights	Yes	No	To ensure that we are compliant with equalities legislation, such as the Race Relations Act 2000, the **Disability** Discrimination Act 2005 and the Sex Discrimination Act as amended by the Equality Act 2006.
Accessible Environment	Yes	No	To provide a forum for service users, including those with **disabilities**, to discuss issues affecting access to the site and buildings.

APPENDIX R4.1:

PARTICIPANTS OF PRELIMINARY NOMINAL GROUP

Twenty three (23) participants took part all of whom were attendees of the nurse induction programme. Information about the participants, collated from a sheet circulated at the start of the group is presented in the table and charts below. No other information (such as name, ward, and ethnic group) was recorded about the participants as they had been assured of the anonymity of their input to the group. Participants were asked about their age, designation (role or band) and the number of years since qualifying. This was so a profile of participants could be compared to that of the follow-up NG (NG2).

Table 4: Profile of participants of NG1

Number of participants of NG1	23
Banding / designation	
Nurse manager	0
Band 8 (egg matron)	0
Band 7 (egg ward sister/ charge nurse/ clinical nurse specialist / practice educator)	2
Band 6 (egg junior sister)	3
Band 5 (egg staff nurse)	18
Age	
20 – 29 years	14
30 - 39 years	4
40 - 49 years	3
50 - 59 years	2
60 – 69 years	0
Years since qualifying	
Average years	6.94
Median years	3

Figure C Age of participants of NG1

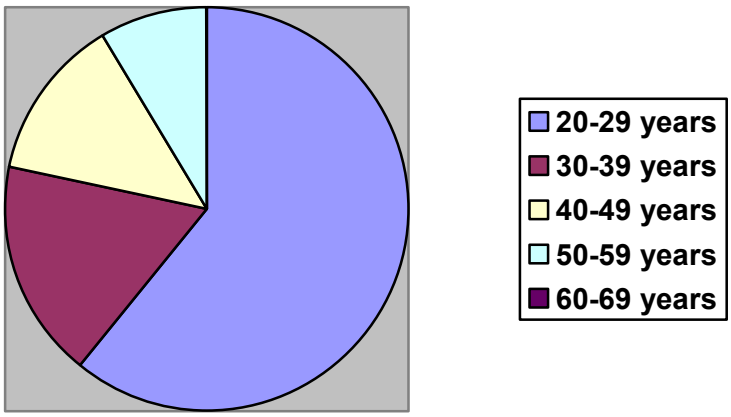
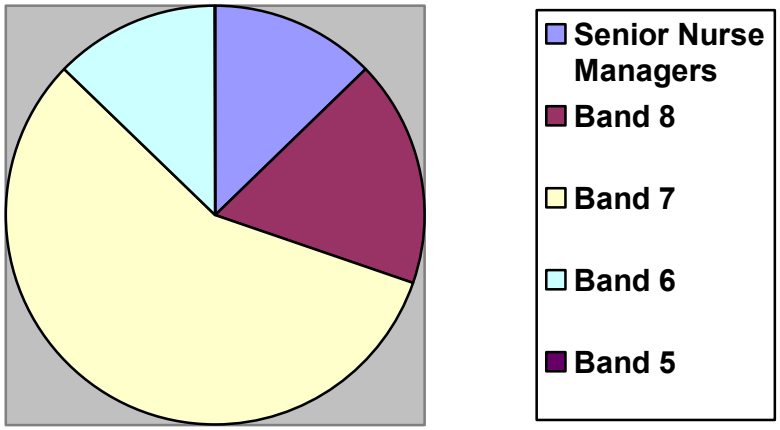


Figure D Banding of participants of NG 1



APPENDIX R4.2:

PARTICIPANTS OF FOLLOW-UP NOMINAL GROUP

Twenty eight (28) participants took part all of whom were senior nurses, or nurses deputising for their more senior colleagues. Information about participants (namely their age, designation (role or band) and the number of years since qualifying) collated from a sheet circulated at the start of the group is presented in the table and charts below. This was so a profile of participants of this group could be compared to that of the preliminary NG (NG1).

Table 6 Profile of participants of NG2

Number of participants of NG1	28
Banding / designation	
Nurse manager	2
Band 8 (e.g. matron)	1
Band 7 (e.g. ward sister/ charge nurse/ clinical nurse specialist / practice educator)	18
Band 6 (e.g. junior sister)	6
Band 5 (e.g. staff nurse)	1
Age	
20 – 29 years	4
30 - 39 years	8
40 - 49 years	9
50 - 59 years	7
60 – 69 years	0
Years since qualifying	
Average years	17.02
Median years	14

Figure E Age of participants of NG2

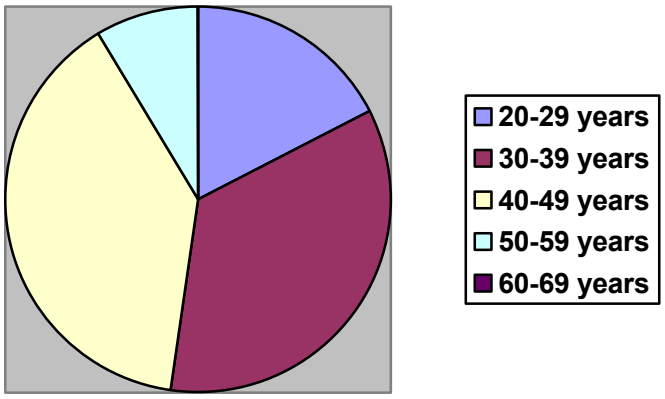
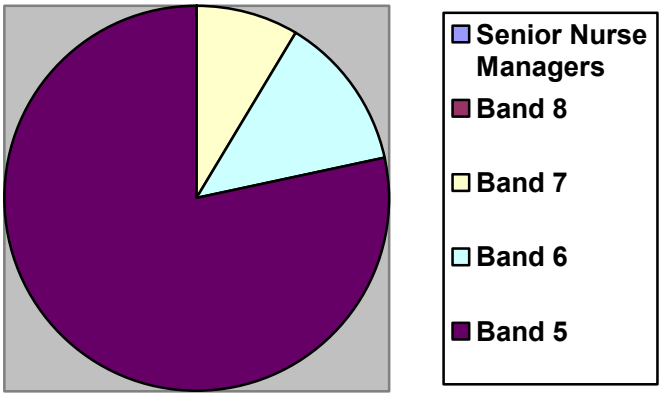


Figure F Banding of participants of NGT 2



APPENDIX R4

COMPARISON OF NOMINAL GROUPS NOT RELATING TO CONSENSUS

Other comparisons between the groups, not relating to consensus of opinion, revealed that fewer feedback forms were produced by NG2 participants (2 forms) than by NG1 participants (8 forms). This could have been due to several reasons. Participants of NG1 were attending the nurse induction programme, on which the use of evaluation forms is commonplace; this could have increased compliance as participants were used to providing feedback at that time. The time taken to conduct NG2 (85 minutes) was longer than that for NG1 (63 minutes), therefore the participants of NG2 may have felt more time pressured and not inclined to complete the form (whilst NG2 did not overrun on the Sisters' Meeting agenda, another session followed immediately). Another reason could have been that participants of NG2 did not have any feedback to supplement the outcomes of the NG, which in turn could have meant that they felt they had had the opportunity to express all their opinions. The feedback from NG1 participants suggested that they had found the group itself interesting ("This session has made me think about things") whereas the feedback from NG2 participants was focused on the effectiveness of the passports ("Passports seem like an excellent move forwards"). None of the participants of either group contacted the facilitator afterwards regarding questions, concerns or further information.

An interesting observation was that the participants of NG2 seemed considerably more comfortable being involved in group work. From the notes made from the facilitator's observations, NG1 participants seemed to be more reticent as the group commenced, where as NG2 participants appeared relaxed and readily took on board the task of generating ideas. In addition, the discussion in NG2 was more extensive and explorative as it involved personal experiences, whereas in NG1 discussion was mainly focused on consolidation of ideas. Despite NG2 participants being notably more comfortable with group work, differences in levels of compliance between the two groups were not detected.

APPENDIX R5:

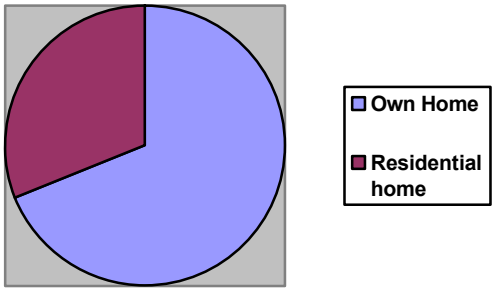
BREAKDOWN OF RESPONSES TO QUESTIONS OF EVALUATION OF PATIENT EXPERIENCES

The responses of the patients/carers were thematically grouped where appropriate, for example responses such as “don’t know” and “not sure” were assigned to the same category. The results of each interview question are presented below.

Question 1: Where were you/the person admitted to hospital from?

11 patients were admitted to hospital from their own home and 5 from residential/ group homes. This information was collected in order to show the settings in which patients were identified as requiring passports. The learning disability nurses would then be able to analyse their case loads to ensure that the passports are promoted, through education and information dissemination, and become available where there were needed.

Figure I: Location from which patient was admitted to hospital



Question2: Was the passport used as soon as you/the person went into hospital?

All 16 responders said that the passport was used as soon as soon they / the patient went into hospital.

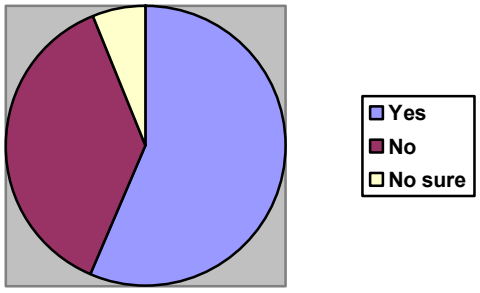
Question 3: How was the passport used in the clinical setting?

All of the sixteen responses described the passport as something to hand over, or issue, to the nurses, for example “I showed it to the nurse and the consultant” and “for nurses to look at”.

Question 4: Did the passport make a difference to the plan of care and treatment provided?

Nine patients thought the passports did make a difference to their care, six were not sure and one said no. This question did not elicit explicit information about which aspects of care were affected, such as the quality of care, patient / nurse communication or resulting health outcomes.

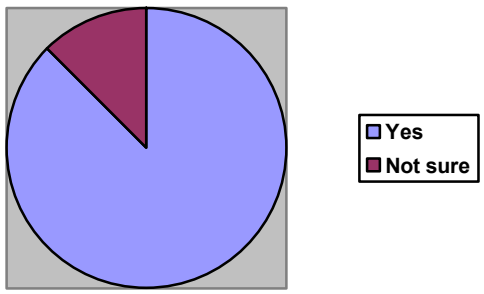
Figure J: Patient perspective of whether passport made a difference to their care



Question 5: Was the passport helpful?

14 responders said the passports were helpful and two were not sure. This shows that the responders recognised that the passport was helpful even if it did not make a different to the plan of care and treatment provided (see question 4).

Figure K: Patient perspective of whether passport was helpful



Question 6: If it was how and why was it helpful?

The fourteen people who responded that the passports were helpful were asked why they thought it was helpful. Responses indicated awareness that the passports supported communication by containing information; for example:

"Everyone knew where to look to find out about me"

"It showed people what was wrong with me"

"It helps people to get on with me"

"The nurses seemed to understand what she liked, such as looking out the window"

Question 7: What things would you like to change or think should be added onto the passport?

This question generated only three responses, which were:

"I don't want to change it"

"Need more space to write in some places"

"Photos might be better instead of pictures"

Other responders were not sure, or did / could not answer the question.

Question 8:Any other comments?

Only three responders opted to provide additional feedback in answer to this question; all three comments suggested a positive stance:

"It's really good"

"Staff seemed to be aware of the passports and knew what to do with them"

"I know of one of our other residents who needs one of these"

APPENDIX C1: OUTLINE OF PRESENTATIONS OF THE PROJECT FINDINGS TO COMMITTEES AND GROUPS

The presentations will take about 30 minutes and will:

- Provide a background to the project in terms of evidence base and legislation
- Outline the consequences of not providing an accessible service to people with learning disabilities (use excerpt from Death By Indifference)
- Provide overview of the outcomes of the organisational review and baseline data (profile of local service users with learning disabilities.
- Explain how the project was set up
- Demonstrate the hospital passport and explain how it has been used /it to be used
- Convey the findings of the nominal groups with staff
- Support this with findings of the semi-structured interviews with patients
- Explain next steps:
    - How are we rolling this out? (Continuing with passport use within the organisation, addressing training issues, rolling out to other groups of service users who could benefit from passports etc)
    - What can THEIR committee / group do? (Does it need to respond and if so how?)
- Contact details if they have any questions.